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INSTITUTE ON NUTRITION SERVICES IN MENTAL RETARDATION PROGRAMS

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March 20, 21, 22, 1963

U. S. DEPARTMENT of HEALTH, EDUCATION, and WELFARE
Welfare Administration
Children's Bureau

INSTITUTE ON NUTRITION SERVICES IN MENTAL RETARDATION PROGRAMS

March 20, 21, and 22, 1963

CINCINNATI, OHIO

A REPORT

SPONSORED BY

Ohio Department of Health
Ohio Department of Mental Hygiene and Correction
Hamilton County Diagnostic Clinic
Children's Hospital Research Foundation, Cincinnati
and
U. S. Department of Health, Education, and Welfare
Welfare Administration, Children's Bureau

U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

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INTRODUCTION

This Institute was the second on the general subject of nutrition and mental retardation. The first was held at Chapel Hill, North Carolina, June 5 to 7, 1958 under the sponsorship of the North Carolina State Board of Health, the School of Public Health of the University of North Carolina, and the Children's Bureau of the Department of Health, Education, and Welfare. Although it was directed toward the small number of nutritionists and dietitians who were already active in programs or services for children suffering from mental retardation, the report sought to incorporate information that would be helpful to nutritionists and dietitians who might be involved in such programs and services at a later date.

Whether or not the report of the first institute had been a factor, as the lively demand for copies may indicate, participation of nutritionists and dietitians in clinical services for mentally retarded children has increased considerably in the past five years. By 1963 the time seemed to be ripe for bringing together nutritionists, dietitians and allied workers for a second institute in order to explore their function in services for mentally retarded children and to consider ways of strengthening and extending the nutrition component of clinical programs. The institute was planned to provide opportunity for sharing experiences on current services and methods of handling problems. It aimed also to present knowledge concerning services and programs.

As the seat of a clinical program in health services for mentally retarded children that has been the recipient of grant-in-aid funds from the Children's Bureau through the Ohio Department of Health, Cincinnati had obvious advantages for the Institute. The sponsors included not only the Federal and State agency already mentioned but also the Ohio Department of Mental Hygiene and Correction, the Hamilton County Diagnostic Clinic, and the Children's Hospital Research Foundation.

Of the 107 individuals registered for the Institute, approximately half were public health nutritionists from State or local health agencies in 35 States, the District of Columbia, and the Commonwealth of Puerto Rico. Another 12 nutritionists or dietitians came from clinical programs in mental retardation in hospitals, health centers, or resident facilities. The inter-disciplinary character of nutrition services to mentally retarded children was evidenced by the participation as learners, consultants, or discussion leaders of physicians, dentists, nurses, social workers, psychologists and specialists in speech and hearing, physical therapy, occupational therapy and biochemistry.

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AN OVERVIEW OF PUBLIC HEALTH PROGRAMS AND SERVICES TO THE MENTALLY RETARDED

Rudolf Hormuth*

Public health programs and services to the retarded are an identifiable component of any total balanced program for this group. Like a toddler, this component of public health services and programs is exploring many areas. It has a lot of growing to do, but it has been conceived, delivered and survived its early infancy. Public health programs for the retarded are now ready to stand on their own feet and explore and test out the surrounding world.

The application of public health approaches to the problems of mental retardation and the utilization of public health channels to meet the needs of these handicapped children required the bringing together of a variety of interests, pressures, and needs. Readiness, skills, resources, support, identification of problems and solutions had to occur in a particular developmental sequence.

A Receptive Framework

The Children's Bureau's concern for mentally retarded children stems initially from its responsibility under the Basic Act of 1912 to "investigate and report on all matters pertaining to the welfare of children and child life." The passage of the Social Security Act in 1935 afforded the Bureau an opportunity to help the States develop special programs in areas where there were gaps in services. Health services to mentally retarded children had been one of these gaps.

The Emerging Problems

Before 1940, most of the severely damaged infants did not survive, and the general feeling about those who did was that little or nothing could be done for them. Between 1940 and 1950, many changes took place in the American way of life that had a dramatic effect on the problem of mental retardation. The United States had the biggest baby boom in history. As the population increased, so did the number of mentally retarded. Better care of all babies and medical advances resulted in the survival of more babies destined to be retarded. They began living longer, too. Mothers and fathers of retarded children began to band together to seek help for their children. By 1950 the organized groups of parents set out to learn how their long neglected children could be helped and what was needed to help them. In their efforts, the parents enlisted a variety of resources, including the Federal Government, and specifically the Children's Bureau.

*See Attendance Roster in Appendix for title and address.

A Beginning

In 1954 the mentally retarded were cited by the Children's Bureau as being particularly disadvantaged and requiring special attention. To evaluate what could be done for this group, the Bureau through its health service grant-in-aid program assisted four States in 1955 in setting up special projects designed to demonstrate how clinical services might be developed.

Some Support

Testimony before the House Appropriations Committee in 1956 by the National Association for Retarded Children indicated that the principal needs for the mentally retarded children were to find them early, to make complete evaluation, to interpret the findings to their parents and to use the findings as a basis for ongoing help and care. To achieve these goals, the Congress increased the annual maternal and child health appropriations for the fiscal year 1957 and earmarked one million dollars specifically for special projects serving mentally retarded children. These were the beginnings of the Children's Bureau's major program emphasis on mentally retarded children and were also the first steps in a large scale public health attack on the problem.

The Special Clinical Demonstrations

The Core of this attack on the problem of mental retardation has been the special clinical services for this group. Under the stimulus of this emphasis the number of clinical programs in this country has grown from 4 to 109 in the past six years. Seventy-five of these are still receiving some support from Maternal and Child Health or Crippled Children's Funds. Of the 54 States and jurisdictions, 48 are providing as a part of their public health program special clinical services for mentally retarded children.

Over 500 well-qualified specialists are serving as the basic teams in these programs. An equal number of consultants from a range of specialties participate in these services, which reached approximately 36,000 children and their families in 1962. Three out of four children served were under 9 years of age. Of those under 6 years of age, 75 percent had associated physical handicaps in addition to the mental retardation.

The most dramatic development of services has been in relation to inborn errors of metabolism such as phenylketonuria. In approximately half of the states, urine screening for PKU is now a routine procedure in well-baby clinics. Nearly 500 children, diagnosed as having PKU were cared for at some point in the last five years by maternal and child health and crippled children's programs. Almost half of these are still under dietary supervision of these programs or the staffs of the special clinical programs administered by them.

Less dramatic but equally important has been the strengthening of basic health services to all mothers and children which has occurred as a result of these core clinic programs. Consultation by the special clinic staff to well-baby clinics has resulted not only in the ability of clinic personnel to carry a number of defective infants, but has materially sharpened their skills in dealing with all babies.

Shortcomings in professional preparation of public health personnel have been pinpointed. This has resulted in a number of institutes and seminars on growth and development. The development of clinical programs within universities and medical schools has strengthened pediatric teaching in the medical school and has taught professionals how to work together as a team.

Some Goals and Trends

Some 5,000 clinics of the type developed would be required to serve all preschool children suspected of being retarded. This is obviously an impossibility. The answer as to how to spread services probably lies in assisting the private medical practitioner (especially the family doctor) to do a more effective job in detecting and managing retarded infants at home. Part of this goal will be achieved in time through bringing into the medical school curriculum newer concepts of management and care. The development of special clinics as a part of a medical school appears to be an effective way of introducing some of these newer concepts on a demonstration service basis.

A more immediate concern is the physician already in practice. In order to assure that the 7 out of 10 parents, who first turn to their family doctor when they become aware of a developmental lag or deviation in their infant, will receive adequate care and counseling, direct and effective measures need to be evolved. The clinics are being made more readily accessible to physicians as consultation sources for help with their private patients. The clinic director is increasingly available to assist in physician referrals and non-medical team members are finding more time to work with the private physician.

As already indicated, in 75 percent of the children under 6 years of age seen in the clinics, multiple handicaps are present. There is an increasing need to work closely with the crippled children's program and to use consultants from a variety of areas relating to problems of physically handicapping conditions. A trend in the clinics is towards "children's rehabilitation centers," out-patient facilities which can deal across the board with children who are physically handicapped and/or mentally retarded.

The importance of a strong crippled children's program with which an effective cooperative relationship can be established has likewise become increasingly clear. The progress that clinics for retarded children can make with a child who is retarded but also has a cleft palate and a club foot is limited unless these physical handicaps can be repaired. The special clinic can help make the corrective surgical efforts easier and more effective, while the child as a whole is able to respond more fully after surgery. A most significant trend has been the development of a few special clinics for retarded handicapped children as a part of the crippled children's program.

Of equal significance has been the reaching out of these special clinics and through them the whole range of health department services to day training centers, nursery programs, special education programs, residential institutions, vocational training programs, etc. For example, nutritionists from health departments have been asked to provide consultation to day training centers. We see a very definite trend of a closer working relationship between maternal and child health programs and health departments and other agencies and services who also serve some aspect of the problem of mental retardation. The working relationship and cooperation is beginning to extend beyond the problem of mental retardation to all service areas.

Coming of Age

Public health efforts along with increased activity in other programs served to convince some people that perhaps some of the retarded could be helped. The currents affecting major changes in public attitudes stemmed from much more fundamental sources, however. The National Association for Retarded Children through its organized national promotion of its cause was changing the climate of the problem. Mental retardation was becoming acceptable--even fashionable in philanthropic circles. Legislators, governors, tax payers and professionals were ready to consider newer approaches to the problem.

The President's Panel on Mental Retardation

The activities of the President's Panel on Mental Retardation is the first step towards these newer approaches. The report of this group of experts has highlighted our needs, and given us a blueprint for action. These necessary steps outlined by the Panel as essential for developing a program of national action to combat mental retardation focus on eight major areas: Research and scientific manpower; prevention; clinical and social services; education; vocational rehabilitation and training; residential care; the law; public awareness; organization of services--planning and coordination.

Health services to the mentally retarded have received prominent mention. Of particular significance to us are the following: Programs to prevent mental retardation need to be emphasized; more research is needed but a great deal about possible prevention measures is already known; known preventive measures are too infrequently applied in program services; the lower socioeconomic groups, especially in the large cities contribute a disproportionately large number of the mentally retarded to our nation; there is a definable relationship between prematurity and mental retardation, between prematurity and lack of prenatal care, and between women who receive no prenatal care and the lower socioeconomic groups in urban areas; the services of the crippled children's programs need to be extended more fully to the mentally retarded; special clinical services for the mentally retarded need to be expanded and extended.

A Response to the Panel Report

In response to the report of the Panel, President Kennedy outlined a specific action program in his special message to Congress of February 5, 1963. The proposals for the Department of Health, Education, and Welfare total $204,723,000 for fiscal year 1964, an increase of $76,219,000 over the current fiscal year. Included in these proposals are the following five amendments (HR 3386) to the Social Security Act: (1) Grants for planning comprehensive action to combat mental retardation; (2) increase in maternal and child health services; (3) increase in crippled children's services; (4) project grants for research relating to maternal and child health and crippled children's services; (5) project grants for maternity and infant care.

New Directions

With this increased emphasis on services for the mentally retarded, we should be able to explore more fully the unique contribution and role of public health programs and

services for this group. The expansion and extension of clinical services should make it possible for the staffs of these programs to play a more prominent leadership role in community planning and in coordination of these services with institutions, sheltered workshops, and day training centers. The strengthening of basic maternal and child health and crippled children's programs should permit us to explore and develop both primary and secondary preventive programs and to further test out the application of newer public health measures such as genetic counseling services to this problem. The application of the total skills and resources of public health programs and services to the problem of mental retardation should not only assist us in developing a total balanced approach to those who are retarded, but should provide us with the tools with which we can effectively achieve control and prevention of the problems of mental retardation.

AN OVERVIEW OF PUBLIC HEALTH PROGRAMS FROM THE VIEWPOINT OF PARENTS' NEEDS

Notes from Presentation of

Gunnar Dybwad, J.D.*

The National Association for Retarded Children works to obtain services needed by mentally retarded children and their parents through its more than one thousand State and local groups scattered widely over the country. Participants in the Institute were urged to make their potential services known to NARC groups in their geographical areas.

Scope of the Problem of Mental Retardation

It is estimated that one billion dollars per year is spent by Federal, State and local governments, by private organizations, and by families in caring for the approximately 5 1/2 million retarded individuals in this country. Of this total expenditure, about 40 percent goes for the building, replacement, or operation of facilities for institutional care although only 4 percent of the mentally retarded are living in institutions. Only 15 percent of the total ($150 million per year) can be identified as being spent on the 96 percent of the mentally retarded who are living in the community. Failure to provide adequate community services means that some children who might learn to care for themselves never do so. They may eventually be admitted to institutions at considerably greater cost than would have been involved in good care in the community.

Since the provisions of the Old Age and Survivors' Insurance category of the Social Security Act were amended in 1957 to provide extended benefits for children over 18 who are unable to care for themselves, the mentally retarded have constituted two-thirds of the group for whom these benefits have been claimed. Helping the mentally retarded to attain their maximum potential is based on economic as well as humanitarian considerations.

Needs of Parents of Mentally Retarded Children

The needs of parents are primarily to have the needs of their children met. To date, programs have been focused too much on parents and as a consequence have not been of much help to either parents or children.

Prejudice against the retarded individual compounds the problem and semantics may be a tremendously important factor in creating prejudice. Categorizing the child as "educable, trainable, or custodial" is likely to mean that he will not rise above the group to which he has been sentenced. It is much more frightening to parents to term an individual "a mongoloid" than to refer to him as "a child with mongolism."

*See Attendance Roster in Appendix for title and address.

When an inflexible diagnosis is made, it often limits the opportunities for development. "Mongoloid" idiots were once excluded from special classes for retarded children. They were automatically consigned to custodial care at State institutions. Because of the label, they were denied opportunities to learn and use abilities that we now know can range well into the educable group.

The notion that retarded children cannot be taught to eat anything but strained baby foods may be the first link in a chain of deprivation that has consequences for long-term physical and social development.

Emerging Concepts of Care for Mentally Retarded

Under the stimulus of the Report of the President's Panel on Mental Retardation and sage advice from individual leaders in other countries as well, program emphasis is shifting from research and diagnosis only, to broad programs of treatment and management. Encouragement is being given to treating the mentally retarded child as much as possible like his normal siblings. Providing facilities that will enable him to remain in the home and community and, if possible, to work in a sheltered environment as he grows older are in his interests and those of society.

The National Association for Retarded Children can open up opportunities for health agencies to serve the mentally retarded. Health workers are urged to approach the task with wholesome skepticism and to take time to evaluate the effectiveness of their efforts.

DEVELOPMENT OF FEEDING PATTERNS IN CHILDREN

Effie O. Ellis, M. D.*

The rapid progress in the field of nutrition is exciting to the imagination and is illuminating paths to new discoveries and challenging scientific concepts of the development of feeding patterns.

I shall attempt to discuss the subject in broad terms. Such a generalized treatment necessarily will be more descriptive than analytical and more selective than comprehensive. Hopefully, some values will accure from review of specific guidelines and important landmarks.

In all matters affecting the health and well-being of children, the stage of their growth and development determines the plan of management and type of services which are to be provided. It is essential to keep in mind that feeding pattern formation cannot be spoken of to the exclusion of the physical, emotional, and social aspects of development. Mental functioning parallels general physical functioning. Specific functions develop in relationship to over-all structural and functional growth.

Changes in size, ability, and behavior occur with great rapidity, particularly in the early years of a child's life. In order to recognize deviations from this constantly changing norm, it is necessary to understand the basic sequence of developmental milestones which normally occur as one evolves from infancy to adulthood. It is only through such understanding that both subtle and striking differences in personal service needs can be recognized and met.

In the strictest sense, the first year is the most important period of life and on its arrangement and course of events depends a very large part of the subsequent adult performance. It is fitting, therefore, that considerable emphasis be placed on this period of beginning.

Feeding should be provided on the basis of the infant's physiologic need, taking into consideration the stage of neuromuscular development. The time of appearance of various reflexes serves as an indicator of an infant's readiness to take foods of varying type and consistency. Further, these reflexes indicate the degree of central nervous system function. Those reflexes which are necessary to life develop earliest and others develop in an orderly sequence as overall growth and development proceed.

The role of the healthful environment cannot be overemphasized. Feeding is closely interwoven with emotional development. It therefore follows, as Caplan and others have repeatedly pointed out, that the emotional climate surrounding the feeding experience is a critical factor in both the acquisition of specific skills and in the child's total development. Emotional unfolding, physiologic functioning, social behavior, and intellectual stimulation are controlled to a great extent by the quality of interpersonal relationships.

Immediately after birth the infant takes a breath, utters a cry of protest, and a human life begins. In this initial stage of extrauterine existence the infant is equipped with potential patterns of unlearned behavior. His responses are completely reflex. He is

*See Attendance Roster in Appendix for title and address.

entirely dependent upon the environment. Crying is the infant's language, his only means of communication. At this stage, needs relate largely to the satisfaction of hunger.

Vigorous peristaltic contractions of the empty stomach are the physiologic basis of hunger. There is wide variation in the frequency and intensity of these contractions from infant to infant. Several recent radiological studies of the actual emptying time of the stomach of newborns demonstrate this wide variability among infants. Likewise, these studies emphasize the variation in time required for the stomach to empty in the same infant under varying conditions. Gastric evacuation is influenced by numerous factors. Physiologically, slow tonic contractions of the muscular wall of the stomach, the pressure relationships in the stomach and the duodenum, play a role in initiation of the process. The cessation of hunger contractions is controlled by enterogastrone which is secreted when ingested material reaches the duodenum. Emotional factors can alter peristalsis and lead to alteration in physiologic function. Following the intake of a certain amount of food, satiety is reached. This point of feeding satisfaction is mediated through the hypothalamus but conditioning plays an important role.

A. Newborn Period and First Year

1. Hunger contractions occur shortly after birth and an individual pattern of rhythmicity evolves within the first few weeks, the basis of the flexible feeding schedule which permits feeding in response to the infant's hunger rhythm.

2. Important reflexes concerned with feeding:

   a. Rooting reflex

   b. The sucking reflex is the neuromuscular indication that the infant is ready to accept liquid feedings. Sucking ceases when hunger has been satisfied. The amount of feeding required for satiety varies from feeding to feeding and day to day.

   c. The protrusion reflex enables the infant to push out food placed on the anterior third of the tongue. This action is at times interpreted by parents to mean that the infant dislikes the food which is being offered. Quite to the contrary this reflex is indicative of neuromuscular unreadiness for acceptance of solid food. Disappearance of this reflex marks the beginning of readiness for introduction of semi-solid foods.

3. Chewing. Between 7 and 9 months the infant exhibits chewing motions. This is the signal for introduction of lumpy foods.

4. Self-feeding. Feeding is an overall learning experience for the infant. By the end of the first year the average infant is neuromuscularly ready to engage in some hand to mouth feeding. The extent of neuromuscular development determines the skill with which self-feeding is carried out. Parents should permit an infant to learn to feed himself when is is ready to do so.

5. Appetite development. During infancy hunger controls the intake of food. In the latter part of the first year, appetite becomes an important factor. Cultural patterns exert a strong influence on conditioning the hunger-appetite mechanism. The food likes and dislikes of the family determine the food choices which will be offered to the infant.

B. Second Year

By the age of one year, the child's diet and habits begin to blend with those of the family group. Food requirement drops when the rapid growth of the first year is completed. If food is offered in a quantity comparable to amounts taken in the first year, normal children will refuse much of it. Lack of understanding on the part of parents concerning the reason for decreased food requirement leads to frustration and major feeding problems.

The development of feeding habits is closely related to discipline. The second year of life is a period of effective habit training. It is during this time that a child passes through a period of negativism, characterized by "No! No! No!" to everything, including food. If the behavior is not understood and attempts are directed toward forcing food, the child learns to refuse food because refusal encourages attention. In spite of the fact that this is also a stage of constant mobility and constant exploration, the child is becoming more positive in his demands. Feeding can serve as a pivot for the development of many undesirable habits. Limits of feeding behavior must be established by the parents. Here, as in all other developmental areas, discipline is essential. Young children are susceptible to parents' demands if parents are firm when a command is given. Ideal discipline consists of permissive behavior within certain limits; however, the limits must be constant, well defined and maintained by both parents. Food should be put before the child without comment. The child should not be asked to make choices.

C. Age Two to Three Years

Feeding problems of an emotional nature are extremely common in the second and third years of life. These problems arise primarily because due consideration is not given to the child's natural fluctuations in desire and need for food. Parents are often too insistent on having a definite amount of food eaten regardless of the consequences. Such insistence creates anxiety on the part of both the parent and the child and disturbs the parent-child relationship. It should be pointed out that children are both imaginative and imitative at this stage. Good food habits are best learned by parental example.

D. Ages Three to Five Years

It is between the ages of 3 to 5 years that the appetite declines to the lowest level of the entire childhood period. These are the years of slowest growth and food requirements are related to growth. Parents who are given guidance as to the meaning of the preschool child's decreased need for food avoid much anxiety and worry.

E. Pre-Adolescent Years

By the eighth year the child begins to grow faster and eat more. Nonconforming behavior characterizes this period of growth. This type of behavior is often misunderstood by parents. A number of feeding problems may be recognized for the first time largely because they stand out in the overall picture of emotional turmoil. Some feeding difficulties are direct outgrowths of unresolved problems of preceding stages, related to

parent-child attitudes which have centered around feeding. Other problems are the result of inequalities between demand and expectations of parents or teachers and the ability of the child to satisfy these demands. Overeating associated with obesity, anorexia, nausea, vomiting may occur as a reflection of a deep unmet emotional need. Understanding of the child's natural development and added tension is the key to successful solution of the problems of this stage. The school assumes responsibility with the family for perpetuating and strengthening good eating patterns and correcting undesirable ones.

F. Adolescence

During adolescence, appetites grow to great proportions. The chief problem here is adherence to good eating habits which we will assume have been established. Influences of the family, the peer group, nutrition education, and advertising each play a part in the determination of adolescent eating patterns.

The development of good feeding patterns presents a special challenge to all workers in the field of child health. Interpretation of normal growth and development to parents in a framework of anticipatory guidance is the key to prevention of numerous problems.

PRESENTATION OF THREE CASES

Jack H. Rubinstein, M.D., Shirley Fischer, Jeanette Allen, Lusia Hornstein, M.D., Jane Perrin, M.D., Dorothy Sievers, Ph.D., Frances Gunter, Barbara Umbarger, Charles Keohan*

The afternoon session focused on the presentation of three cases by clinical teams from the Hamilton County Diagnostic Clinic for the Mentally Retarded in Cincinnati. As an introduction to the Clinic and its method of team evaluation, the Director, Dr. Rubinstein, showed and discussed slides, illustrating the respective roles of the team members and how their functions and services are coordinated after a period of evaluation in a team conference, where diagnostic impressions are formulated and treatment plans are established.

The first case presented was that of "Johnny," a six and a half year old boy, living in a boarding home since the age of one year, and handicapped by brachial phocomelia (congenital absence of arms, hands attached to shoulders). This patient's medical history and the results of his physical examination were presented to Dr. Rubinstein, followed by reports from the public health nurse, social worker, and psychologist involved in Johnny's evaluation. The clinic nutritionist presented Johnny's feeding history, placing emphasis on the fact that he had received little stimulation or opportunity to experiment with biting, chewing, messing or handling of food items in the foster home where there were about 11 non-ambulatory, severely mentally retarded children. Johnny's feeding habits were considered quite immature for his age. Psychological testing indicated Johnny was functioning close to the 3-year level. After reports were presented by the various team members, Dr. Rubinstein reviewed the diagnostic impressions and recommendations.

The second case presented was that of "Suzy," a four and a half year old girl with mongolism. Reports were again presented by the various team members, with the pediatrician presenting the medical aspects of the case, the social worker presenting information about the family's social situation, the clinical nurse presenting some of the health aspects of the case, and the nutritionist presenting the early feeding history and feeding problems. Suzy had been indulged by her parents to the point that she was permitted to control the feeding situation and was currently accepting only "goodies," such as potato chips, candy, soft drinks, ice cream, cereals and hamburgers prepared by a local chain of restaurants. The treatment plan and recommendations resulting from the team conference included that of further nutritional counseling.

The third case presented by the team was that of "Elizabeth," a thirteen month old girl, first child, one of twins, delivered with a prolapsed cord. Parents were both 25 and college graduates and there were personal and family problems, including disagreement about possible placement of the patient. Home care was difficult, suctioning was required. As with the previous two cases, their respective reports were presented by the pediatrician, clinical psychologist, public health nurse, nutritionist and social worker. The diagnostic impressions included: severely mentally retarded functioning, diffuse motor dysfunction and rigidity, swallowing difficulty, awkward grasp, and motor delay. There was also caloric undernutrition. Further counseling by the clinic nutritionist was included in the recommendations growing out of the team conference.

*See Attendance Roster in Appendix for titles and addresses.

DISCUSSION

Leaders: Frances Shoun, Helen Hille, Margaret Dunham*

Each group used one of the cases presented by the staff of the Diagnostic Clinic as the starting point for considering the nutritional aspects of health services to mentally retarded children. It was agreed that the case studies had value in: (1) providing a focal point for group thinking on a specific situation; (2) moving the discussion from the specific to the general situation; and (3) leading to the formation of basic concepts of good nutrition service. The three groups tried to come up with some answers to the following questions: (1) What was the function of the nutritionist in each of the three cases? (2) How can nutritionists work most effectively as members of a multi-disciplinary team and with members of their own profession? (3) How can nutritionists be better prepared for work in mental retardation programs?

Nutritional Aspects of Each Case

Case One. Discussion centered around the implications of the foster home situation for nutrition services to the boy with brachial phocomelia. Suitable foster homes for handicapped children are hard to find. The lack of stimulation for Johnny as a consequence of the more severe mental retardation of the other children and the indulgent attitude of one of the foster parents was offset at least in part by the good physical conditions in the home and the kindly interest of the parents. The most promising channel for improving Johnny's nutritional status and developing the potential he had already indicated for feeding himself seemed to be through the nurses and social workers who were in continuing contact with this home. They in turn would profit by regular consultation with the nutritionist familiar with the case.

Case Two. It was agreed that Suzy's nutritional problems were not related basically to her mental retardation, but rather to the food situation in the home and the attitudes of the parents. Improvement in her nutritional status could be achieved only as the several members of the clinical team would deal with the problems that lay within their respective areas of competence and would call upon the nutritionist for intensive service as indicated.

Case Three. Awareness of the complex situation was considered of primary importance in dealing with Elizabeth's nutritional problems. The professional background of the young parents, the normality of the twin, and the fact that the employee who cared for the children during the day was herself the mother of a retarded child -- all these factors called for the most careful dovetailing of the various professional services to the family. Direct service by the nutritionist in the home might obtain reliable information on the food actually ingested and retained by this child with such severe feeding difficulties and throw light on the apparent lack of correlation between her food intake as reported by the parents and her nutritional status. The nutritionist's findings would have many implications for the other professional workers in continuing contact with the family.

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*See Attendance Roster in Appendix for titles and addresses.

The Nutritionist as a Member of a Multidisciplinary Team

For effective team work in combatting mental retardation, it is essential that there be mutual recognition of the functions of each member and appreciation of the interdependence of those who make up the team. The nutritionist has to make sure that her colleagues understand what they can expect from her; then she should try to give a little more service than could reasonably be expected. It is easy to gain recognition for her dramatic contribution in dealing with inborn errors of metabolism; but it may be even more important to demonstrate what she can do in behalf of the much larger number of children suffering from less clearly defined forms of mental retardation. Intradisciplinary cooperation can also be of major significance in dealing with the nutritional aspects of mental retardation. The nutritionist who works with the hospital or other institution caring for mentally retarded children can help to promote the all-important continuity of care.

Preparation of the Nutritionist for Her Role in Mental Retardation

Basic courses at the undergraduate or graduate level should lay a sound foundation in child growth and development, the nutritional needs of normal children, and techniques of feeding at various stages of development. Students should also be made aware that the approach to people in stress situations must be flexible. Dietetic interns and graduate students of public health nutrition should be given an orientation to the clinical problems associated with mental retardation as a foundation for more intensive on-the-job training for those who will work in mental retardation programs.

In-service education is needed to increase the scientific and technical knowledge of the nutritionist and her understanding of how to work with members of other professions, with community agencies, and with parents' groups. The nutritionist would profit from actual experience in a facility caring for mentally retarded children where she might acquire familiarity with such matters as the mechanics of feeding children with multiple handicaps. In-service education undertaken with individuals from related professions may increase competence in making a concerted attack on common problems. Not infrequently a nutritionist who participates as a teacher in in-service education of individuals from another profession is a learner at some of the sessions for this group.

Continuing Opportunities for Development

The typical nutritionist working in a mental retardation program is isolated from other nutritionists similarly engaged. She needs the stimulation that comes from an exchange of materials and ideas, and from having some central source to which to turn for information. Periodically, taking part in institutes or workshops refreshes competence.

ENDEMIC CRETINISM

A Travelogue

Josef Warkany, M.D.*

With the assistance of colored slides taken mostly in picturesque mountain valleys of Austria and Switzerland, Dr. Warkany traced the almost complete conquest of endemic cretinism, a form of severe physical and mental retardation related primarily to dietary deficiency. Even before the relationship between lack of iodine and the development of goiter was established, seaweed had been recognized as valuable in its treatment. With the introduction of iodized salt, one canton in Switzerland reduced the incidence of mental retardation associated with endemic cretinism by 85 percent. Although progress in the mountainous regions of Austria was impeded by Hitler's prohibition of the sale of iodized salt beginning in 1938, the iodine content of the diet increased with the use of cod-liver oil and the introduction of foods grown outside the region of iodine-deficient soils. At the present time in Europe, endemic cretinism is found only among adults in the most isolated mountain valleys. It is more prevalent in certain primitive areas, such as the interior of New Guinea. By and large, the disease has been eliminated even though all the factors in its etiology are not completely understood.

*See Attendance Roster in Appendix for title and address.

INTRODUCTION

Ernest Johnson, M. D.*

Providing opportunity is the most important factor in feeding a multihandicapped child. Sometimes the chief obstacle in the home situation is the parents' lack of acceptance or even their denial of the child's condition.

Parent counseling is very important and too often lacking. In counseling with parents we should help them to wait for the child's maturation, meanwhile working with him where he is.

* See Attendance Roster in Appendix for title and address.

THE PHYSICAL THERAPIST

Barbara Ostermeier*

This presentation took the form of a film showing the development of feeding skills in a group of thirty children with multiple handicaps who were patients in a state hospital. At the outset of the training project, only 2 of the children, whose ages ranged from 6 to 15, were able to feed themselves. Although the institutional staff who were in immediate charge of carrying on the project were undertrained and overworked, 15 children had learned to feed themselves with spoons or fingers by the time the film was made. Some of the aids illustrated were: tables and chairs of the proper height, eating utensils with easily grasped handles, suction cups to secure the plate or tray to the table, foods that were easy to handle (animal crackers are readily picked up), and bibs that make spilling a minor matter. Although these aids were helpful, they were less important than providing the individual child with the opportunity to develop whatever capacities he might have for self-feeding.

*See Attendance Roster in Appendix for title and address.

THE OCCUPATIONAL THERAPIST

Ruth Hadra*

As a member of a therapy team, I am concerned with helping the handicapped child achieve independence in self-care. Whether total or only partial independence can be accomplished depends on several factors such as: (1) degree of handicap; (2) developmental maturity; (3) motivation and drive; and (4) family's attitude toward the handicapped child.

As an occupational therapist, my goals in working with the cerebral palsied infant include: (1) improvement of coordination; (2) development of basic functions of reach, grasp and release; (3) teaching concepts and patterns of motion, all of which develop without specific training in an infant whose neuromuscular system is intact. I see children who cannot reach for nor grasp a block, who are unable to build a tower of blocks or throw a ball. A child who lacks the motor control to grasp a toy cannot successfully grasp a spoon. If he cannot build a two block tower, he also lacks the accuracy it takes to place a cup on the table without spilling.

A child who is unable to feed himself is not necessarily undernourished. If he is satisfied in retaining the status of an infant, he may not have nutritional problems as long as there is someone taking care of him. But many severely handicapped cerebral palsied children gradually resent the hand that feeds them and refuse food because they are tired of being fed or tired of getting only soft food. If speech is lacking, the child is unable to express his feelings by talking. Not infrequently the non-verbal child communicates negative behavior through the only bodily movements he is capable of making, such as arching of his back, stiffening of arms and legs, attempts to slide out of his chair or stand up in his chair, pushing his tongue out of his mouth, extending his jaw, spitting his food out, or simply crying. Such behavior adds more tension and anxiety to the whole process of eating.

When we talk about feeding the child with multiple handicaps, we must go a step further and ask ourselves: (1) What are some of the specific symptoms that make it necessary to feed the child? and (2) What can be done to achieve self-feeding or at least partial self-feeding? The ability to feed oneself is an advantage not only because it relieves a member of the family or an institutional attendant but also because it is a more satisfactory emotional experience to the child than dependence on others.

I am going to use slides to discuss the feeding behavior of three young cerebral palsied children who have severe motor handicap of all extremities. All are considerably retarded in over-all function, and lack speech. Each one had a complete diagnostic work-up prior to the age of three and prior to their referral for treatment at the Cerebral Palsy Center in Cincinnati. Since total body function is severely impaired and they are unable to handle test materials or give verbal answers to an examiner's question, intelligence, comprehension and the ability to learn have been difficult to assess.

The first seven slides are of a 3-year-old girl. They illustrate the complexity of the feeding process as it relates to total body function. Too often we seem to be only concerned with chewing or swallowing.

SLIDE 1 shows a tonic neck reflex. This neck reflex pattern is noticeable in normal infants up to about 4 months of age, but it often persists considerably longer in the severely involved cerebral palsied child. It is one of the most difficult patterns to break.

*See Attendance Roster in Appendix for the title and address.

The physical therapist is working with the occupational therapist to help the child achieve control of the reflex.

SLIDE 2 shows her with the physical therapist. The child is beginning to hold her head up but cannot sit without support. This child's motor development is below the level of a 6-months-old infant. However, after having observed her responses in therapy over a period of 6 months, we feel that comprehension is above her level of motor control. She communicates through bodily movements and sounds and can indicate a "yes" and "no" response through appropriate head movements.

SLIDE 3 shows the child with the occupational therapist and points out how the tonic neck reflex affects basic arm motions. We who live in a "right-handed" world tend to place a spoon on the right side of the child. Naturally the child will turn his head to the right. When the tonic neck reflex is still active, the arm subsequently extends and the entire upper extremity is in a locked position of extension. The child cannot open the fingers or bend the arm at the elbow, a necessary movement to place food in the mouth.

SLIDE 4. In order to get away from the locked arm position, the child has to turn her head toward the center. The toy is placed in the center of the table by the therapist in order to motivate the child to turn her head. This child has a considerable amount of involuntary motion, and it takes several attempts before she succeeds in grasping the toy.

SLIDE 5 shows an activity the child is not yet ready to do alone, but can complete with assistance. Placing the ring on the cone stresses here an eye-hand coordination which is important for self-feeding, or even for being fed.

SLIDE 6. Here the child is actually grasping the cookie with her first three fingers while her parents observe her.

SLIDE 7. The child is actually bringing a cracker to her mouth--not well, but is is a beginning of a self-feeding pattern. The cut-out in the table provides support for the trunk as well as the arms of the child who cannot sit independently. When we began working with this child 6 months ago, we asked the parents whether the child had a chair, how she was fed, and what kind of food she ate. We were told that she had a high chair, a stroller, and a carseat, but had never sat much. The mother fed her in her lap. We instructed the father in adapting the high chair to the child's present needs, making the seat smaller, making a cut-out tray instead of using the small regular tray which came with the chair. The child has not been shifted completely from her mother's lap, but being fed in the chair has been accomplished partially. Frequently, feeding in the mother's lap is prolonged because the mother is unable to detach herself from the complete care of the handicapped child.

If the child has difficulty with chewing and swallowing, or with tongue movements, being fed in a reclined position is not good and one should work toward an upright position. This child eats mostly table food now. Meat is chopped up. She has fairly good lip closure, but some involuntary opening of the jaw and forward motion of the tongue.

To summarize: The factors keeping this child from self-feeding are the tonic neck reflex, lack of trunk balance, poor reach and grasp. We cannot expect her to manage feeding utensils, such as a spoon or cup, until she controls the tonic neck reflex, until she can sit independently, and until she gains better arm control. Chewing and swallowing are not too much of a problem. The child is definitely motivated.

SLIDE 8 shows a 6-year-old being fed by his mother. His handicap is similar to that of the younger child, but even more severe. When he was younger he had a severe extensor thrust of the whole body. He still has a tonic neck reflex, poor head control, no

sitting balance, no grasp. He is now able to sit in a small wheelchair which has been very helpful in his total management.

SLIDE 9 shows the therapist demonstrating to the mother how she should feed him. The head is slightly supported and tilted forward.

The third child, aged 18 months, is severely retarded. She demonstrates reverse swallowing with the tongue coming forward. Her mother was instructed to feed her small helpings and to get her to remove food from the spoon with her lips instead of sucking on the spoon and to have her to sit in a chair.

Summary

Feeding is a very complex pattern of head and trunk control eye-hand coordination, chewing, sucking, swallowing. Not every cerebral palsied child is a feeding problem. In some whose physical handicap is mild, mental retardation presents a feeding problem. The child may have all the physical components necessary for self-feeding, but does not understand the feeding concept. Such children are being fed because they are not given a chance to do it themselves. Mothers often cannot take untidiness, and the cerebral palsied child is likely to be untidy for quite some time. The mother who cannot tolerate playfulness needs to be told that playing with the spoon is a normal thing in any child.

RELATIONSHIP OF FEEDING AND SPEECH

Bernard Schlanger, Ph.D.*

The nutritionist and speech therapist are related distantly--kissing cousins, I would say, by mouth. You are interested in what goes into the mouth--I am interested in what comes out. Can you talk without moving your tongue, lips, teeth? Probably the best exercise for the speech act is the manipulation of these parts in eating a good steak.

Nine out of ten mentally retarded children may have various speech difficulties. Some of the problems are due to neuromotor difficulties, some to sensory handicap, others to psychological problems. Speech difficulties may or may not be related to the cause of the retardation. Mental retardation, then, is not an entity but a variety of behavioral symptoms, some of which can be changed. I mention this since I will be talking about feeding and speech. This means that young children will be discussed, and diagnosis in the infant and preschooler is not adequate unless the child has obvious stigmata--the mongoloid for example, or the child with gross motor handicaps, such as the cerebral palsied. Even with the latter children there is a period of waiting in order to be certain that intellectual subnormalcy exists.

In the meantime there are certain obvious activities that encourage the child and prepare him for speech. Speech is a physical, learned act. We use mechanisms that are primarily involved in life functioning--such as the breathing apparatus used as the motor or power for voice. The larynx becomes the phonator or noise-maker; our sound is given distinctive characteristics, which enable most people to recognize us over the phone, by relationships of throat, nose, cavities and muscle tonus, the amount of mouth opening we use. And last, but not least, we shape the sounds of our language by tongue, jaw, lip and soft palate movement--swift and relatively concise movement.

Speech adapts the chewing apparatus to strive for intelligibility. Before the child learns to speak, he must be able to chew, suck, blow and swallow. The severely retarded child may have difficulty with all of these functions. I worked with an 11-year-old mute athetoid child who would not chew or suck. I thought that gum drops might be a good incentive to promote chewing motions. He did not like gum drops, chewing gum or anything sweet. As a matter of fact he took liquids only, swallowing with a minimum of effort by having his head tilted back. His mother had made no attempts in his earlier years to train him in feeding but through pity and her martyrdom had kept him at an infant stage. She should have realized that function, chewing in this instance, helps the body develop to the best of its inheritance. Conversely, maldevelopment can result from a lack of functional stimulation and/or unbalanced relationships of muscles and dental structures, due to acquired habits. Without the healthy exercising patterns of jaw, facial musculature and tongue, the health of many potentially healthy babies is seriously impaired. Without exercise the lower jaw often fails to catch up to the upper jaw. The correct jaw articulation does not take place when the first teeth appear. Since the retarded has so many strikes against him, it is necessary to develop his healthy eating and swallowing habits. With underdeveloped mandible and related musculature the child has a tendency to allow his lower jaw to hang open. His tongue then assumes "lazy" detrimental habits, protruding or remaining inert, cradled in the mandible.

In addition to chewing, correct swallowing patterns are necessary for food assimilation, for good mouth hygiene which involves the continual bathing of teeth and tissues

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with saliva, for healthy dental arch form for the positioning of teeth. The tongue is one of the strongest and most active muscles of the body. With incorrect swallowing, reverse swallow, you exert great pressure against teeth. Many children who swallow this way thrust the tongue out and typically may have problems with sounds made with the tip of the tongue against the gum ridge, such as s, z, t, n, and l. The orthodontists and speech therapists who have become mutually interested in this problem feel that it may be related to use of nipples which require the baby to place his tongue against the hole to stop the "easy flow." On the other hand, breast feeding requires a great deal of work on the part of the infant. Attempting to emulate nature, a German company has manufactured a nipple which in many respects compares in its activity requirements with breast feeding. I mention this because there appears to be a high incidence of tongue-thrust among children with cerebral palsy, mongoloids with their underdeveloped upper jaw, and other retarded children. If this nipple is accepted, I can see hordes of future babies singing the opening line of the Communist International, "Arise ye prisoners of starvation."

If the child is ill or badly-nourished, speech may be delayed.

1. He may be unable to take foods except from a bottle for a much longer time than the normally developing child.

2. He may drool long after most children learn to manage saliva because of:

   a. lack of facial muscle and tongue control as in cerebral palsy

   b. poor jaw and teeth structure.

What helpful suggestions can be made to the parents?

1. If possible, the child should be made aware of his drooling. He should learn to close his mouth, particularly while eating, and make his tongue work.

2. Foods with chewy rough texture such as nuts, celery, apple and pear slices should be given him.

3. Activities which might be used to increase his strength and control of facial muscles would include: Blowing horns or feathers, making faces, sticking tongue out as in licking lollipops, licking lips with honey or jelly smeared on them.

4. Drinking from a tube with lips closed should be attempted.

5. Standing behind the child, directing food, holding jaw to eliminate its action in swallowing should be inaugurated.

6. The child might feel his throat when swallowing to make him conscious of the act.

In feeding the child with multiple handicaps, efforts should be made to get him to feed himself. If the mother of the boy I mentioned earlier who would not chew had done the following, he might have had good feeding habits and been speaking:

1. Made the child use his lips in taking food from a spoon rather than scrape it off with his teeth;

2. manipulated his jaw, told him to chew, and showed him how to chew;

3. put food on one side then the other rather than in the center on his tongue so that he would have had to move the food around with his tongue.

Other suggestions that might have been given to her, and other parents of children with neuro-muscular difficulties and intellectual deficit might include:

1. Using foods with lumps and hard texture--let the child break off pieces of toast, for example;

2. use large bright foods, such as carrots, lettuce, bananas;

3. try new foods when the child is hungriest.

These are the suggestions that apply to the motor acts of the child with handicaps--both physical and mental. He has to use muscle to eat--and to speak.

What of the psychological nourishment--the motivation to speak? Eating time is an excellent period to reinforce speech. Eating is pleasurable. Every child knows the pleasure of eating. It is almost instinctive to direct the thumb--which must taste delicious--to the mouth. During the meal, conversation should be directed to the child. Short sentences and the naming of foods accompanied by smiles will motivate him to eat and speak more than frowns, nasty voice tones and other punishing stimuli.

All kids are messy eaters. The child with multiple disabilities is even more so. Emphasizing good table manners and cleanliness can discourage the child's appetite and his need to speak. He needs to be allowed to struggle, and the hardest thing for the parent is to hold back and permit him his hard won independence.

Guilt often accompanies and dictates the attitude of the parent to his handicapped child. A retarded child in the family strikes at the pride of the parents. To compensate for these feelings the poor child may be stuffed with food, becoming even duller and possibly sicklier. This is something it would be wise for any of us to be aware of as we work with the retarded child and his family.

The parents of the mentally retarded child need good guidance in all areas of his development. Speech and eating, because of their physical and psychological relationship, need special stress. Good feeding habits promote good speech--and a corollary to this is that a good feeder can be a good speech therapist.

DENTAL ASPECTS

Robert L. Holle, D.D.S.*

In Cincinnati, we have nine dental clinics which are associated with the University of Cincinnati, College of Medicine, Dental Department. Associated with these clinics, we have a training program whereby dentists are trained to provide dental care for the handicapped, that is, those individuals who are suffering from cerebral palsy, mental retardation, and rheumatic heart disease; also nephritics, nephrotics, post-polios and others. Many times the parents of these children consult with the dentist, not only for dental care but on routine feeding problems. We all agree that it is vitally important for these children to have a good efficient oral apparatus to prepare the food for proper assimilation. These handicapped children already have several strikes against them, so we must improve their health by providing proper dental care and by helping them to secure the proper diet to get the most out of their food.

Common Misconceptions of Parents in Reference to the Teeth of Mentally Retarded Children

1. Many parents believe that the teeth of the handicapped are different from other persons'. This is not true. These children have the same number of teeth and the same size and shape. They have the same calcium salts, histological formation, and suffer the same pathological conditions as anyone else.

2. Many parents believe that because their child is mentally subnormal his teeth do not have the proper calcification--in other words, that the teeth are "soft." This is a layman's misconception. Generally speaking, most everyone's teeth have approximately the same amount of calcium salts and the same calcium deposition.

3. Many parents believe that medicines cause cavities in children's teeth. So many times when we examine a child's mouth and find excessive amounts of dental decay, the mother volunteers: "Well I gave my child iron, and immediately afterwards his teeth started to rot." This is not true. It is rare that any medications taken orally can cause any appreciable amount of dental decay.

4. Many, many times parents will say: "Well, my children's teeth are just so soft that the fillings don't hold, and it just isn't worthwhile to fix them up again." This old, old story of course is not true. Many times the parents feel that the teeth decay from the "inside out." It is absolutely impossible for this to occur. Invariably when we find excessive decay, the history indicates that there has been an excessive intake of sweets, carbonated beverages, and chewing gum.

Often the parents neglect their children's teeth because they are uninformed. Sometimes there is an indifference to the fact that this child has a horribly broken down mouth. This is most unfortunate, since children with mental retardation have toothaches too, just like you and me. Simply because they have some neuromuscular involvement does not preclude their having dental care; in fact, they are more deserving than you and I because they already have other difficulties. The least we can do for them is to prevent dental pain.

*See Attendance Roster in Appendix for title and address.

Difficulties in Assimilating Food

(1) A malocclusion is a condition where the teeth do not meet properly. Many times this can be corrected by proper orthodontic intervention. Mentally retarded children who have a moderate or severe malocclusion have a definite decrease in their chewing efficiency. The child with poor occlusion will have difficulty masticating his food to the proper texture so that it can be absorbed from the alimentary tract.

(2) Likewise, many mentally retarded children have suffered from a loss of teeth through extraction. Unfortunately, many dentists are afraid to work on these individuals and they simply tell the parents to have the bad teeth pulled when they give trouble. If there are not enough teeth to be efficient in masticating, the individual will have difficulty in preparing the food for proper absorption.

(3) Many mentally retarded children, especially mongoloids, have a large tongue. This causes an expansion of both the upper and lower arches, and often results in malocclusion which again will prevent the proper mastication and assimilation of food.

(4) Another condition called bruxism (the grinding or gnashing of teeth) many times will cause the cusps or bumps on the teeth to be worn off and result in decreased chewing efficiency and loss of vertical dimension or closure of the bite. This, once again, can ultimately result in decreased chewing efficiency and more difficulty in assimilation of the food.

Poor Eating Habits

Many times, mentally retarded children simply don't eat; especially when they have an extensively broken down mouth. Some reasons why these children do not eat properly are:

1. It probably hurts to chew their food. With teeth rotted off to and under the gum, it is painful to bite down on something hard or an exposed nerve.

2. With lack of teeth due to extractions, the chewing mechanism has lost its efficiency. The child does not receive the necessary nourishment, and his body does not develop properly. A vicious cycle is set up.

3. When broken down teeth are abscessed, the child most certainly absorbs toxicity from this infection. Many times the child will become lethargic and lose his appetite.

Ways of Dealing With Some Problems

1. Children who will not chew or swallow their food--who "simply don't eat"--should be given a high caloric diet and vitamin supplements. The proper consumption of milk is also quite important. In cases of allergies to milk, calcium tablets should be supplemented so that the child has the necessary calcium intake for the proper construction and formation of the teeth and bones.

2. Some children with mongolism or cerebral palsy have a condition of hypersalivation. Other mongoloids have a condition called xerostomia or dry mouth. In

individuals who have an excessive amount of saliva, the food should be dry. When there is a lack of saliva, a moist food should be provided so that it can be swallowed easily.

3. Mentally retarded children often have a quite active gag reflex. In these children soft foods that can be easily swallowed are indicated. Many times the pharynx or throat is quite wide open, so it is very easy for these children to gag or choke on some types of food, especially liquids.

4. Children who receive dilantin, an anticonvulsant to prevent seizures, get a hypertrophy or overgrowth of their gum tissue. Sometimes this tissue is rather soft and easily scratched; therefore, a soft diet is recommended to prevent trauma.

5. A few individuals have an achlorhydria. The therapeutic hydrochloric acid in passing over the teeth will cause decalcification. A help to many of those who have to take such caustic and strong drugs is to provide a straw whereby they can suck the medicine up and back to the pharynx and eliminate its passage over the teeth.

6. Knives, forks, and spoons with large plastic handles, which can be easily grasped by the spastic cerebral palsied and mentally retarded individuals and aid them to sit at the table and eat like other individuals, are of assistance in the overall feeding problem. They help children to assume their position in society.

THE NUTRITIONIST AND A DEAF-BLIND CHILD

Doris E. Lauber*

Mrs. X, a mother of a deaf-blind child, called me for suggestions on how she might teach her 4-year-old boy to chew foods. In addition to being both deaf and blind, Timothy X was also born with a defective heart. At birth the doctors predicted that he would not live more than 3 months. Given excellent care by his parents and physicians, Tim survived beyond their expectations. When his mother called for advice, he was to undergo corrective heart surgery. If the surgery was successful, Mrs. X wished to be prepared to teach Tim to chew his food.

Tim did have successful surgery and made a prompt recovery; however, he soon contracted influenza and later a head cold. As a consequence, the mother has not as yet made much progress with Tim's feeding problems. Tim will eat only when held on his mother's lap. She feeds him pureed foods from a spoon and water from a cup. Tim chokes or gags on any form of solid food, and refuses milk or anything else that is unfamiliar. Tim's present weight is 22 pounds.

In response to my inquiries, the Perkins School for the Blind, Watertown, Massachusetts; the Industrial Home for the Blind, Brooklyn, New York; and the American Foundation for the Blind, New York, New York, were all generous in sharing their experiences with us. Some of their suggestions which Mrs. X will be trying with Tim include the following:

1. Let the child fully explore food by getting his hands in it, smelling it, and tasting the different varieties of food. All children like to explore foods; the deaf-blind child will need to explore longer, perhaps and may create more of a mess, but he needs this experience with food.

2. Place the child's hands on your face so that he can feel the chewing motion. Most infants, and this includes 4-year-old Tim who is infantile in behavior, pat and caress their mother's face while they are being fed. Next, place the child's hands on his own face so that he understands that he can do the same motion. Be relaxed and pleasant, so that he learns that eating and chewing are pleasurable experiences. Repetition is important in teaching the child to chew, so repeat during each mealtime the placement of his hands first on your face, then on his. Constant physical contact appears to be a good method of teaching him.

3. Teach the child to bite by helping him to hold a bit of graham cracker and guide his hand to his mouth. The graham cracker is easily dissolved so he will not choke on it. He may spit it out during the first few tries. You can help him bite by pushing the cracker up gently on the point of his jaw.

4. After the child has learned to bite, he is then ready to chew. Cheerios are sweet, melt rapidly, and seem to be a good food to use in helping the child to learn to chew. Other foods that have been successfully used are cooked peas, Rice Chex, fresh pears, fresh peaches, and apples. Do not give the child bite-size pieces before he learns to bite or chew, as he might choke.

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*See Attendance Roster in Appendix for title and address.

5. When there is great difficulty in teaching the child to chew, a small cube of cheese can be placed on the back lower teeth. The cheese is soft yet chewy, and the child will have to chew to dislodge it.

6. Show the child how pleased you are with every step of progress he makes.

In Tim's case, the parents have been over-protective, since, understandably, their chief concern was in keeping him alive prior to his heart surgery. Mrs. X will need to follow the infant sequence of adding new foods, introducing foods with different and coarser textures, and, finally, teaching Tim to eat table foods. Many deaf-blind children cling to favorite foods which offer a form of security, and Tim is no exception. However, there has been success with one suggestion. Since Tim refuses to drink milk, he now has dry milk solids added to his pureed foods. Mrs. X reports that Tim is "doing better" since his surgery than ever before. He will soon have a hearing evaluation, and shortly thereafter, will be seen at the Child Development Center for a complete evaluation. Mrs. X is looking forward to this evaluation, as she is anxious to help Tim to develop as far as his potential will allow.

DISCUSSION

Leader: Laura Dittmann*

Even those who are concerned primarily with feeding the handicapped child should look at him in his total life situation and not merely as an eater. Behind each handicapped child are the parents, who have their own level of accomplishment. We must avoid creating in them any feelings of inadequacy as we help them start at the stage of maturation that their child has achieved, and to give him the opportunity to do what he can. Feeding is likely to have emotional ramifications for both parents and child. It helps to reduce the emotional "charge" of the situation to look at eating in relation to the total achievement of the child and not as an end in itself.

Comments relating to the training of professional workers and aides responsible for the feeding of children with multiple handicaps brought out the following points:

1. That films such as those shown are the best possible tools for teaching dietitians and related workers how to deal with the feeding problems of handicapped children and should be made available.

2. That the dietitian should observe the feeding of handicapped children in the hospital or institution so as to understand their reaction to foods of different textures and the variation in their readiness for solid foods. This experience will help her to adapt the foods served to the ability of the children to handle them.

3. The equipment and utensils used by occupational and physical therapists in teaching parents and children self-feeding are not always available in the dining rooms of the same institution. Granted that lack of funds so often makes it difficult to provide this equipment for routine use and that shortage of food service workers places obstacles in applying the techniques taught by the therapists every time the child comes to the table, much can be accomplished by closer communication between the dietary department and the departments of physical and occupational therapy.

*See Attendance Roster in Appendix for title and address.

BIOCHEMICAL DISORDERS RESPONDING TO DIETARY THERAPY

Stanley W. Wright, M.D.*

Two types of disorders were discussed:

1. Those with genetic defect determining a biochemical or physiological abnormality and with response to dietary therapy: phenylketonuria, galactosemia, maple syrup urine disease, nephrogenic diabetes insipidus. These illustrate reversibility of genetic manifestation; importance of early detection and treatment; importance of environmental agents in genetic manifestation.

2. Those without clear cut genetic basis; biochemical defect not known and with some response to dietary therapy: idiopathic hypoglycemia, seizures.

The emphasis was on clinical, biochemical, diagnostic and therapeutic, and genetic features of these disorders. (Slides were used to discuss a number of disorders that respond to diet therapy. The discussion of phenylketonuria and galactosemia paralleled closely presentations in later pages. Dr. Wright's outline for the discussion of other disorders follows. Supplement A of the Appendix consists of a list of references supplied by Dr. Wright to guide further reading.

Maple Syrup Urine Disease

A. Clinical:

1. Onset first few weeks: seizures, opisthotonus, respiratory collapse, death. Survivors--severe mental retardation.

B. Biochemical:

1. Defect in oxidative decarboxylation of branched chain amino acids--valine, leucine, isoleucine. Accumulation of ketoacids and amino acids.

C. Diagnosis:

1. Accumulation of branched chain amino acids and ketoacids in the blood, spinal fluid and increased excretion in urine.

D. Genetics:

1. Recessive trait. Frequency not known. Carrier state not determined.

*See Attendance Roster in Appendix for title and address.

E. Treatment:

1. Diet low in branched chain amino acids. Studies by Dent et al. Studies by Snyderman et al.

Nephrogenic Diabetes Insipidus (Pitressin Resistant)

A. Clinical:

Polydipsia, polyuria. Retarded growth. Mental retardation. Episodes of dehydration and unexplained fever. Hypotonic urine. Specific gravity 1.000-1.0005.

B. Biochemical:

Not known: failure of distal renal tubule to respond to pitressin. Failure to concentrate urine.

C. Genetics:

Sex-linked trait. Mother shows some decrease in ability to concentrate urine.

D. Diagnosis:

Failure to respond to pitressin. No evidence of urinary disease. Failure to concentrate. Hickey-Hare test.

E. Therapy:

1. High fluid intake: normal caloric intake; low solute. High fluid; high CHO, high fat, low protein, low salt.

2. Results (Stroh-slide). Need to institute early before mental retardation.

Idiopathic Hypoglycemia

A. Clinical:

1. Onset infancy with seizures; growth failure.

B. Biochemical:

1. Hypoglycemia. Sensitivity to leucine (and high protein feedings). ? other forms

C. Diagnosis:

1. Glucose tolerance curves: leucine loading tests.

D. Treatment:

1. Steroids

2. Dietary: frequent small feedings; nighttime feedings. Low leucine milk (Wyeth).

Idiopathic Seizures--Ketogenic Diet

1. Of children put on diet: 50% will stay with it. Of these, 50% have some benefit.

2. Petit mal: most favorable response.

3. Ketone bodies must be regularly demonstrated in urine: i.e. acetone, diacetic acid, hydroxybutyric acid.

4. Diet 3:1 fat: CHO. Adequate caloric intake. Cream, butter, olive oil, egg yolk, bacon. No sugar. Protein 1 to 1-1/2 gms./kg.

5. Use of diet very limited today: drugs more effective.

APPLICATION OF THE PRINCIPLES OF DIETARY TREATMENT

PHENYLKETONURIA -- THE METABOLIC RESEARCH TEAM

Betty S. Sutherland, M.D.*

A group of workers pooling their efforts to achieve a total product is not unique in any field of endeavor, certainly not in medicine, and certainly not in the treatment of phenylketonuria. As elsewhere, the group in Cincinnati consists of a team whose duties are closely integrated, and totally interdependent in their goal of permitting a phenylketonuric child to develop an aura of well-being, good nutritional health, proper physical growth and development, as well as peak intellectual capacity.

The biochemist tells the physician when examination of urine and blood shows deficiency states and illnesses which may be averted. The biochemist informs the nutritionist of the ups and downs of phenylalanine tolerance and the presence of unwelcome metabolites which may be indications of needed dietary alterations.

The nutritionist has the difficult task of developing normal feeding habits and the promotion of adequate nutritional intake for proper growth and development, all under the cloak of deprivation.

The physician must set the stage for his co-workers. The indoctrination of the family in the adequate understanding of the illness and the overall plan of treatment is most important from the onset. The physician continues to assess the well-being of the patient as well as the strides made in physical and mental growth and development.

In all phases of treatment the working group receives help from additional team members: the neurologist, psychologist, social worker and nursing staff.

We wish it could be said that the diagnosis having been made, the patient might receive Lofenalac and the problems be solved. But this is not the case. The family with a phenylketonuric child must be prepared to contribute time in the form of repeated visits in consultation with the working group. The child is seen daily for the first 4 to 5 days of treatment at which time daily blood samples reveal the rapidity of fall in serum phenylalanine values. The mother initially takes urine filter paper samples four times a day to show how this particular child deals with the metabolites of phenylalanine. The nutritionist makes her all-important adjustments accordingly during these strategic early days of treatment. Thereafter twice weekly, blood samples show us how the patient is handling the diet. For continuing therapy, serum phenylalanine assessment becomes bimonthly and urine examinations by the filter paper method are done biweekly. The physician and nutritionist see the patient and his family once a week for the first 6 to 8 weeks of treatment, then monthly, and finally four times a year, when the diet is well-established and the patient's responses to it are well known.

(The presentation closed with a series of slides showing phenylketonuric patients manifesting the characteristic presenting symptoms of this disease, or in a few cases the absence of such symptoms. There was considerable variation in their response to the dietary care that all were receiving. A group of older children showed little or no improvement of any kind. Another group of children slightly over 3 years of age improved considerably in behavior. The response was most gratifying in a group placed under treatment below the age of 1 year. A baby whose condition had been diagnosed at 5 weeks eventually attained an I.Q. of 110).

*See Attendance Roster in Appendix for title and address.

PHENYLKETONURIA--BIOCHEMICAL MONITORING OF TREATMENT

Helen K. Berry*

For biochemical monitoring during the treatment of phenylketonuria we use 3 measures: phenylalanine concentration in blood, phenylalanine excretion in urine, and orthohydroxyphenylacetic acid in urine. The methods are given in Supplement B of the Appendix. The use of urine specimens dried on filter paper and mailed to the laboratory enables the mother to obtain the necessary urine specimens easily. The small volume of blood required for the micro-paper chromatographic determination of phenylalanine can be taken from finger or heel puncture. If patients live out of town, blood is sent by mail using microblood collection kits.[1] In some instances the parents, at the suggestion of their local physician, take the blood sample.

A routine procedure is followed for collection of blood and urine specimens as shown in Table 1. At the same time daily diet records are mailed.

TABLE 1.--Schedule for Sample Collection

Period	Blood	Urine
First 3 days	Daily	Daily
3 days - 2 wks	Twice weekly	Daily
2 wks - 3 mos	Weekly	Daily
3 mos - 1 yr	Monthly	Twice weekly
1 year or more	Quarterly	Twice weekly

Results of measuring these substances, phenylalanine in blood and urine and orthohydroxyphenylacetic acid in urine, are shown in the accompanying figures. The data were obtained from two phenylketonuric children who are being treated at present at Children's Hospital Research Foundation. Both children were 12 to 18 months of age at the time depicted in the figures. Both were diagnosed as having phenylketonuria at 9 months of age. These data demonstrate how information from blood and urine studies can be used as a guide to dietary adjustment.

Figure 1 shows an initial period of relatively low phenylalanine intake during November and December (150-250 mg/day). Phenylalanine excretion was low (0-50 mcg/ml) and orthohydroxyphenylacetic acid was not detected in urine. During the end of December and early January, the phenylalanine intake remained constant, but phenylalanine excretion rose from 25-50 mcg/ml to 100-125 mcg/ml; orthohydroxyphenylacetic acid appeared in urine. About January 26 there was an abrupt decrease in phenylalanine intake, accompanied by vomiting and eruption of an acute-dermatitis. Serum phenylalanine 2 days later was 10 mg%. This episode probably represented a phenylalanine-deficiency state: Increased excretion of phenylalanine, increased serum levels of phenylalanine, appearance of orthohydroxyphenylacetic acid in urine--all resulting from a too low intake of phenylalamine--not an excess as one might suppose from the elevated serum levels. As phenylalanine intake was increased during February, serum phenylalanine decreased and urinary excretion of phenylalanine decreased.

*See Attendance Roster in Appendix for title and address.

[1] Sample blood collection kits may be obtained from Chromatography Laboratory, Children's Hospital Research Foundation, Cincinnati 29, Ohio.

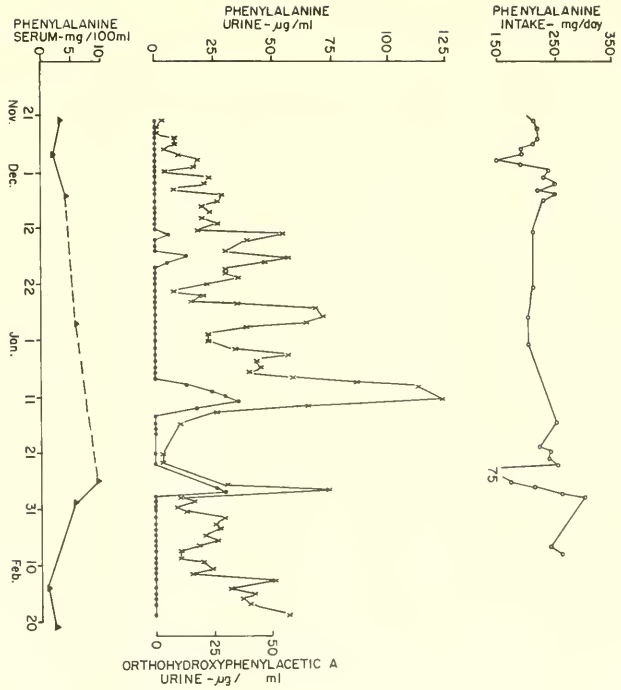

Figure 1.--Chart showing serum phenylalanine, urine phenylalanine, urine orthohydroxyphenylacetic acid and phenylalanine intake during period of relatively low phenylalanine intake and probable phenylalanine deficiency in a treated phenylketonuric child.

Figure 2 begins with a period of good control in January, characterized by serum phenylalanine values between 4 and 8 mg%, moderate excretion of phenylalanine (25-75 mcg/ml) and no detectable orthohydroxyphenylacetic acid. Intake of phenylalanine was high until early February, although serum phenylalanine levels remained in control range, between 4 and 8 mg%. On February 6, 7, and 8 an increased excretion of phenylalanine was noted and orthohydroxyphenylacetic acid was excreted. This apparently marked the onset of a respiratory infection. During the acute febrile phase of the illness (approximately February 9), phenylalanine intake dropped and phenylalanine excretion decreased. Immediately, and before phenylalanine intake was restored to former levels, phenylalanine excretion rose rapidly; orthohydroxyphenylacetic acid excretion increased. Serum

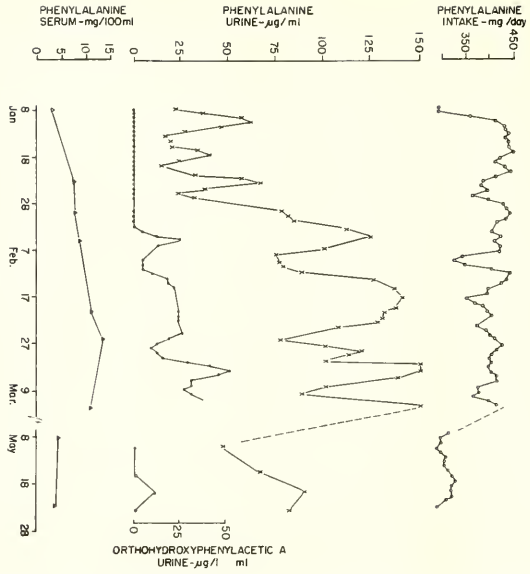

Figure 2. --Chart showing relation between serum phenylalanine, urine phenylalanine, urine orthohydroxyphenylacetic acid and phenylalanine intake during a period of relatively high phenylalanine intake, with series of febrile illnesses, in a treated phenylketonuric child.

phenylalanine levels were not measured during this period; however it is likely that elevated serum phenylalanine concentrations were present. The increased excretion of phenylalanine persisted for the duration of the illness, in spite of the relatively low intake of phenylalanine. The pattern was repeated later in February and in March. Serum phenylalanine concentrations ranged from 4-5 mg% during May. Intake was adjusted to 275-350 mg/day. Urinary phenylalanine ranged from 25 to 75 mcg/ml; orthohydroxyphenylacetic acid was detected on one occasion.

In Table 2, I have summarized the relations we observed between phenylalanine intake, phenylalanine excretion, and concentration in serum in a well child. For this child phenylalanine excretion was 0 to 50 mcg/ml when intake ranged from 200 to 300 mg/day. Serum levels were under 2 mg%. This probably represented a deficient phenylalanine intake. With intake of 275-350 mg/day, serum levels rose to 4-6 mg%; urinary excretion of phenylalanine rose to 25-75 mcg/ml. On phenylalanine intake of 350-450 mg/day, the child was able to eliminate a slight excess of dietary phenylalanine by urinary excretion, without increasing the serum phenylalanine levels markedly. It was not possible to maintain this balance during an illness. Data on a sick child are summarized in Table 3. The onset of a febrile illness was usually preceded by an increased excretion of phenylalanine in spite of a fairly constant intake. The acute phase of the illness, usually accompanied by loss of appetite and frequently vomiting, with consequent decrease in phenylalanine intake, apparently precipitates a phenylalanine deficiency. This leads in turn to increased phenylalanine excretion, increased levels of phenylalanine in blood, and excretion of orthohydroxyphenylacetic acid.

TABLE 2.--Relations between Phenylalanine Intake, Excretion, and Serum Concentration

Well Child (12-18 months)

Intake	Phenylalanine Excretion	Phenylalanine in Serum	Orthohydroxyphenylacetic acid excretion
mg/day	mcg/ml	mg%	mcg/ml
200-300	0 - 50	0.5 - 2	0
275-350	25 - 75	4 - 6	0
350-450	75 - 150	5 - 8	0

TABLE 3.--Relations between Phenylalanine Intake, Excretion, and Serum Concentration

Sick Child (12-18 months)

Intake	Phenylalanine Excretion	Phenylalanine in Serum	Orthohydroxyphenylacetic acid excretion
mg/day	mcg/ml	mg%	mcg/ml
250	125	14	25
275-300	75 - 150	9	12 - 37
350-450	75 - 250	9 - 15	12 - 63

In conclusion, the requirements for phenylalanine vary widely and change with age and physiological state. We need to anticipate the changing requirements. Biochemical control of phenylketonuria is not easily separable from dietary control, for if the biochemical results are not immediately available, there is no firm basis for anticipating the required dietary adjustments. The adjustments in phenylalanine intake are made on the basis of the individual child's ability to tolerate phenylalanine in excess of that required for growth, to eliminate the excess in the urine without increase in blood levels or production of abnormal metabolites. Serum phenylalanine measurements at frequent intervals are necessary for checking the effect of adjustments in the diet. Urinary phenylalanine and orthohydroxyphenylacetic acid measurements provide a continuing record of the ability of the child to eliminate the excess phenylalanine without increasing the blood levels. Increase in urine phenylalanine is frequently the first sign of an approaching illness. Orthohydroxyphenylacetic acid excretion warns that the capacity of the child to utilize or eliminate phenylalanine has been exceeded, and serum levels of phenylalanine have increased.

PHENYLKETONURIA--LOW PHENYLALANINE DIET

Barbara Umbarger*

It seems to us that the effective low phenylalanine diet must serve two purposes: (1) to restrict phenylalanine; and just as important (2) to provide nutritional and other feeding requirements to support optimum growth and well-being.

It is impossible to compose such a diet by simply modifying a normal menu. Restriction of phenylalanine must be so severe that natural proteins cannot be depended upon to supply the nitrogen for growth needs of a child. A synthetic food is needed. Though difficult and costly, a biochemical process has been developed to remove phenylalanine from casein, a good nitrogen source. This process also removes several other amino acids. The next step in making the treatment of phenylketonuria practical has been to synthesize a basal diet mixture with the appropriate balance of carbohydrate, fat, minerals, vitamins and amino acids. Seven or eight years ago we laboriously mixed our own in the laboratory. Since that time several commercial preparations have been produced. Lofenalac made by the Mead Johnson Company is currently used here.

I should like to remind you of what Lofenalac is. (Lofenalac Composition) Appendix B-1.

I should also like to remind you of what it is not. It is misleading to assume that Lofenalac is a complete food for several reasons: (1) it contains no intact protein; (2) it is deficient in an essential amino acid; (3) it contains virtually no fiber; (4) it contains virtually no water; (5) possibly lacks unrecognized nutrients present in natural foods.

In judicious use, the low phenylalanine diet is not comprised solely of the low phenylalanine basal mixture. Instead, we think of it as containing: (1) low phenylalanine basal mix; (2) natural foods to yield required additional phenylalanine; (3) iron supplement; (4) multi-vitamin supplement, as required; (5) sufficient fluid.

When one sets out to design such a diet for a child, certain facts, figures and food lists are needed.

Calculation of Approximate Phenylalanine Content:

	Phenylalanine (mg)	Protein (g)	Calories
Lofenalac			
1 oz. (normal dilution)	3.8	0.6 (as N)	20
1 tablespoon	7.5	1.4 " "	43
Natural food			
e.g. milk 1 oz.	50[1]	1.0[1]	20

[1] Proteins composed of 4 to 6% phenylalanine
1 g = 1000 mg
5% of 1000 mg = 50 mg

*See Attendance Roster in Appendix for title and address.

Most lists of phenylalanine content of foods are estimated on the basis of protein content by means of the simple arithmetic shown. Skill in manipulation of such figures, or even those derived from unweighed and diluted Lofenalac, should not make the dietitian confident that a given child is well treated because of her calculations. They are tools--a means to an end. Concomitant blood and urine studies are necessary aids in helping her readjust her aim.

It may be helpful to consider the phenylalanine requirements of children:

Normal		
1-9 months	41 mg per day (tyrosine present)	
1-13 years	not well established	
With phenylketonuria	Probably 10-40 mg per day	
Varies according to:	(1) age or growth rate (2) individual child	
10 mg		40 mg
over 5 years	small children	infants

The minimum normal requirement shown is far exceeded by commonly used milk formulas. Rough calculation shows 1 quart of milk yields approximately 1600 mg phenylalanine (50 mg x 32 oz).

How does one actually go about applying the low phenylalanine diet for a given child?

Arriving at a Lofenalac formula for an 8 pound infant:

Caloric requirement: 50-55 per (ideal weight) per day = 400-440 calories

Fluid requirement: 2-3 oz per pound per day = 16-24 oz.

1 measure (1 tablespoon) Lofenalac yields 43 calories (normal dilution = 1 tablespoon/2 oz. water)

10 measures + 20 oz. water = approximately 20 oz. normal dilution

$43\overline{)440}$

Distribution of feedings is according to demand.

Initiation of the diet, incorporating above formula, is shown for one infant progressing from day 1 on the diet, day 2, day 3, etc. (series for first several weeks in Appendix B-2).

Several facts regarding this infant's previous feeding were considered while initiating the diet: (1) feeding difficulties with several formula changes; (2) no experience with flavors other than milk; (3) no experience with spoon feeding or texture changes.

In daily diet series please note: (1) the early addition of milk to prevent serum phenylalanine from decreasing to a deficiency level; (2) the precipitous decrease in serum levels during the first few days; (3) the introduction of Lofenalac paste, a familiar flavor but new consistency; (4) the advantage taken of hanger and readiness to gradually introduce different textures and flavors; (5) the introduction of the spoon which paved the way for future acceptance of several types of foods which in turn facilitated our process of "titrating" his serum phenylalanine levels.

The initiation phase of the diet was also an important learning period. The parents were learning to measure and calculate, to understand the need for dietary changes, and to carry out changes with confidence. The child was learning to accept and enjoy spoon feeding, new flavors, and new textures just as his peers on regular infant diets. Were are learning what this child's tolerance and requirements of phenylalanine were, and how we could best guide this particular family and foster its adjustment to treatment. The assessment of urine and blood studies was a vital part of our learning.

Forms which we have found useful in assembling the necessary information for assessment and follow-up are included in the Appendix B-3 to 6.

Sample urine collection kits and blood collection kits were included in the PKU literature packet which was distributed, Appendix B-7. Methods are described in another paper.

The illustration of dietary progression in the child previously used as an example is continued in a composite graph marking the weekly and monthly changes for approximately 10 months of dietary treatment (See Appendix B-8).

The first crucial step in manipulation of the diet for phenylketonuria is the day-to-day planning in initiating the diet. That process, as shown here, obviously would be handled somewhat differently for an older child whose eating experience is more sophisticated. In either case the initiation phase requires special attention. Crucial steps two, three and four were taken during (a) a period of deficiency of phenylalanine; (b) a period of excess phenylalanine; and (c) a period of febrile illness. In each instance the steps are guided carefully by laboratory findings with a minimum lag in communication among the parties involved.

The composite graph mentioned above (Appendix B-8) shows an example of impending phenylalanine deficiency in the early phase of this child's treatment. There was a slight delay in meeting his increasing phenylalanine requirements, which apparently reached a maximum around the fourth to fifth month. Natural food additions during the period accompany the graph.

A period of mild excess of phenylalanine intake is shown on the same graph at the point where the serum phenylalanine levels rose above the range which we consider safe (3-7 mg% by quantitative paper chromatography). The crucial periods cited represent short periods of very mild deficiency and mild excess of phenylalanine intake. This child's progress was actually quite satisfactory in that his weight, height and development were considered excellent throughout.

Pronounced cases of deficiency of phenylalanine intake have been encountered. One example is cited (graphic presentation of correction period, Appendix B-9). A six-month-old patient was sent to us after having been on an unsupplemented Lofenalac formula since the low phenylalanine diet was started at approximately twelve days of age. He had done poorly and had been hospitalized elsewhere several times. Blood transfusions had been necessary. When the child was first seen by our group as an out-patient, conservative additions of natural protein foods of high biologic value were made. When the serum phenylalanine levels failed to respond to our satisfaction and the child's life seemed in

jeopardy, he was hospitalized. His tissues having been depleted of phenylalanine, there was loss of other amino acids and protein synthesis was curtailed. Some vomiting and lack of interest in eating complicated our efforts to remedy the phenylalanine deficiency. During the process of correction, the child--already six months of age and hopefully "normal"--was taught to accept some solid foods. He began to gain weight and soon blossomed into the bouncing, cooing baby which makes this age child so delightful and appealing. The phenylalanine intake in the early months of a well-managed diet is compared to this child's during a prolonged period of deficiency at a similar age (Graph - Appendix B-10). Efforts to adjust phenylalanine intake to meet the increasing growth demands of the infant with phenylketonuria are shown.

The fourth crucial period which I propose to illustrate will be encountered by anyone who guides the details of a dietary program for a child with phenylketonuria. Episodes of febrile illness, contagious diseases, tonsillectomies, etc. will befall children with phenylketonuria just as any other. How does this affect the dietary planning? What does one do about it? One of our objects in guiding the mother in practical application of the diet is to make her so well informed and confident in her efforts that her own judgment and parental understanding will prevent her from forcing the child to eat, special diet or not. A healthy, happy child refuses to eat for a reason, one of the less complicated reasons being the onset and development of a cold, gastrointestinal upset, or febrile illnesses. At such times, a child with phenylketonuria may show a natural lack of interest in eating; a consequent decrease in actual quantity of food intake is to be expected.

However, we have good evidence that the phenylalanine requirement of a child under treatment is probably increased during illness. The delicate balance between sufficient and insufficient phenylalanine intake may be difficult to maintain. During a febrile illness when body protein is catabolized, serum levels of phenylalanine rise. One should not be misled. When this occurs, it is not an indication to withhold natural foods from the diet; instead, the increased phenylalanine requirement should be met by substituting certain natural foods which the child is likely to accept in spite of prevailing conditions. Thus one hopes to avert a lengthy period of puzzling biochemical fluctuations.

Examples of plans for increasing phenylalanine intake during acute illness are shown (Appendix B-11). In general such a plan includes: (1) approximately 1-1/2 times the daily average intake of phenylalanine prior to illness; (2) Lofenalac formula ad lib; (3) water ad lib; (4) "free fluids" containing sugars and electrolytes as prescribed by physician; (5) division of phenylalanine allotment into 4 to 6 small feedings per day.

The following summary lists some of the observations and considerations in working with the young child and the older child, then closes with a brief listing of the requirements for maintaining satisfactory long-term control.

The infant:

1. May have early history of feeding difficulty - colic, pyloric stenosis.
2. New formula, stools change.
3. Initial period on diet requires most vigilance.
4. Examinations, numerous tests--electroencephalograms, blood and urine samples.
5. Mother may be tense, fearful that child will not eat, insistent about feedings.
6. Shock of diagnosis and its implications.
7. Complexity of regime, calculations.

8. Well-meant feeding and diet advice from grandparents, neighbors.

9. Infant not yet familiar with flavors and textures of foods.

10. Appearance and taste of Lofenalac repulsive to parents.

11. Mother fearful of feeding too much phenylalanine

12. Routine menu for ease of calcualtion or fear of refusals.

13. Unwarranted confidence in nutritive superiority of commercial baby foods.

14. Small capacity, concentration of food or Lofenalac.

15. Febrile illnesses.

16. Reluctance to allow others to care for child.

17. Child becomes aware of "forbidden foods."

The older child:

1. Probably retarded, hyperactive, irritable or preoccupied.

2. Infantile eating abilities.

3. Poor muscle co-ordination; weaning and self-feeding skills behind schedule.

4. Food jags and strikes, decreasing appetite as seen in formal children.

5. Negative reactions to rigidity, assertion of independence as improvement occurs.

6. Family sympathy, oversolicitiousness, infantilizing, invalidizing.

7. Fed by others; scavenging, begging.

8. Mother may adjust diet according to behavior.

Long term control requires:

1. Sound parent instruction, supportive follow-pu.

2. Favorable initiation of child.

3. Appropriate dietary adjustments to meet phenylalanine requirements and total nutritional needs.

4. Encouragement of the most mature eating habits appropriate for child's changing developmental levels

5. Allowance for increasing independence and social aptness in child's eating.

6. Avoidance of complete family dominance by this special diet routine.

7. Constant awareness of dealing with an individual and "whole" child.

THE KETOGENIC DIET FOR A CONVULSIVE DISORDER

Michael De Lorenzo M. D. *

(This presentation involved the cooperation of the physician, the patient and his mother. Slides were used to show the details of the diet. Various devices that had proved helpful in daily management were exhibited. The presentation of the pediatrician is available in outline form only.)

KETOGENIC DIET (Livingston)

I Selection of Patients

Age: 3-8 years

Type of Epilepsy: Minor motor of akinetic or myoclonic variety

Cooperation of Parents and Patient (Intelligence, etc.)

Electro-encephalograph Findings: Spike and Wave Forms

II Management

A. Fasting Period - 3 to 6 days - four days with water intake not less than 400cc nor more than 800cc a day to obtain desired degree of dehydration.

B. Drug - Discontinue all drugs except phenobarbital, which is maintained for three months, then reduced gradually over period of subsequent year. Others reduced over three month period.

C. Laboratory Tests -

1. Urine for acetone and acetoacetic acid

2. Carbon Dioxide

3. Blood Glucose Levels

D. Daily Weight - At 10% weight loss and strongly positive urinary acetone, start diet.

III Calculation of Diet (Livingston)

Method most satisfactory:

1. Supply calories required to maintain growth. At 3 to 5 years: 60-80 cal./kg

2. Provide those calories in proposed ketogenic-antiketogenic ratio.

3. Dietary unit fat to carbohydrate and protein = 4:1 ratio = (9x4)+(4xI) = 40 cal.

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*See Attendance Roster in Appendix for title and address.

4. Number of calories needed/day is divided by 40 cal. giving number of dietary units

e.g. Chris weighed 18 kg
18x70 = 1260 cal/day
1260 ÷ 40 = 31.5 units

Each unit contains 4 gms of fat, therefore 31.5 x 4 = 126 gms of fat

Each unit contains 1 gm of carbohydrate / protein. Sufficient protein must be given to maintain growth. This is 1-1.5 gm/kg.

18x1 = 18 gms protein/day
Carbohydrate = 31.5 - 18 = 13.5 gms CHO/day

4:1 diet therefore:		
Fat	-	126.0 gms
Protein	-	18 gms
Carbohydrate	-	13.5 gms
Total		157.5 gms

If progress is satisfactory maintain rates at:

4:1 for 2 years

then 3:1 for 6 months. Calculation: - Dietary unit = (9x3) + (4x1) = 31 cal. Then calculate in same way. Then 2:1 for 6 months (dietary unit = (9x2) + (4x1) = 22 cal.) Then normal diet

IV Other Necessities

1. Vitamins: - B group + C. Brewer's yeast or substitute without starch filler

2. Calcium 1-2 gms/day

3. Daily testing of urine for acetone and diacetic acid

4. Caution in using other medications: (without syrups, elixirs, etc., also tooth-paste, mouthwashes)

5. Constipation - generally not a problem. Mineral oil, Epsom Salts. Because of lack of bulk a bowel movement every 2-3 days sufficient.

In case of decreased appetite i.e. illness, fever, discontinue diet and give 4:1 eggnog or just water.

4:1 eggnog - Dissolve 1/4 grain (15 mg) saccharine in a teaspoon of water and add to 60 gms of 36% cream. Add 20 gms of lightly beaten raw egg and 10 drops of vanilla. Little nutmeg may be sprinkled on top for esthetic effect. Mixture may be diluted with water to patient's taste.

MY SON'S KETOGENIC DIET

Mrs. William Timmer*

Chris is the youngest of our three sons. William Jr. (Tim) is almost 8, John Barth (Bart) is almost 6 and Christopher Paul (Chris) is almost 4 chronologically. He is epileptic and mentally retarded. His mental age is approximately 15 to 18 months.

He was breast fed for three months then graduated to homogenized milk. His eating habits were apparently normal until he was three years of age. He was on a semi-soft diet because of swollen and often bleeding gums, a condition which was caused by the anti-convulsant drugs which were used to control his epilepsy.

He has fed himself by hand since he was approximately nine months old. He rejected a spoon even when offered by me at approximately 3 years. Perhaps this was a result of his aggravated gum condition.

The control of his seizures was not as effective as we desired and in September 1962 he was admitted to Children's Hospital and placed on the ketogenic diet to treat his epilepsy. This treatment has been infinitely more successful than treatment by anti-convulsant drugs. He seems to us more alert and active, he plays with toys, even has a favorite (his Punkie pillow). His seizures are less frequent and much less severe.

The period of starvation which Chris had to undergo in order to reach the desired acidity to enable his body to utilize the ketogenic diet was difficult for us because his appetite has always been superb. However, the fact that he could not talk and could not directly ask for food made it easier for us to bear, also the fact that he was in the hospital and under constant vigilance and care was a great comfort to us.

The first days of feeding under the keto-regime seemed very slim to us, his anxious parents, but we were informed that we needed to test his tolerance of the high fat content of his food. His acceptance of the bland, fatty foods was heartwarming and he never wavered from complete consumption of each article on his tray. As far as we are able to ascertain, he has never been less than 2 plus in his acetone tests which are used to evaluate the successful amount of ketosis. He is now on a level of 4 plus continuously. We were instructed by hospital personnel on the procedure of testing the urine for acetone.

When we took Chris home after ten days of the diet, we immediately tried to step up the amount of food for each meal. We had access to a complete list of a wide variety of foods, and the composition of each as it pertained to carbohydrates, protein and fat. We bought a gram scale and thus were able to figure the four to one ratio for an infinite variety of food combinations.

One of the most difficult phases of this ketogenic diet has been the exacting correctness which must accompany all calculations for the diet. My nature is rather of the give-and-take variety; my tempo of life is helter-skelter. My family, my husband and the Diagnostic Clinic team of Dr. Rubinstein, Miss Umbarger and Dr. DeLorenzo from Children's Hospital have been a tremendous help in this matter. For parents, the close feeling of being allowed to view and attend the examinations, to be instructed how best to help your child and to be considered a part of the group working for the welfare of your child is the most precious and finest piece of work done by the Diagnostic Clinic.

*See Attendance Roster in Appendix for title and address.

Our records and bookkeeping sometimes fail, but the diet never. My housekeeping and sparetime activities are sometimes ignored, but Chris always has a diet with a 4:1 ratio and a 4 plus acetone reading.

We have found a variety of short cuts helpful in maintaining a family feeling of love and care for Chris and one another.

Chris wears a football helmet to protect him from the unexpected falls which often accompany a seizure.

Each particle of food that is given to Chris is first weighed and calculated with the other items on the menu to see that the combined total of protein and carbohydrate units are 1 to the 4 units of fat in the meal.

At first we were over the amount of calories allowed for Chris and he gained weight. Now we have learned to temper our enthusiasm and to maintain a correct weight gain for Chris.

During a recent illness we were faced with the possibility of not being able to maintain ketosis -- because medications with a syrup base (decongestants, etc.) are laden with sugar or honey. Any medication with a syrup or an alcohol base is not compatible with a diet which excludes even toothpaste. With the advice of our pediatrician working with the Diagnostic Clinic, a cough syrup was devised of equal parts of lemon juice, Sucaryl and pure aspirin (acetyl salicylate) to be given 1 teaspoon every four hours. This cough syrup and continued use of the vaporizer overcame a fever of 102 to 103 degrees and congestion. He suffered no after effects from this illness. His general health, aside from epilepsy, is excellent.

We use Dryper pads (a disposable paper diaper) along with extra heavy training pants to spare us embarrassment when he wets. This also protects him from chill and recurrent colds.

Chris drinks from a cup with a spout -- there are less spills this way. Instead of regulation socks that most little boys wear, our son wears stretch tights. It is easy enough to untie a shoe and remove a sock -- it's a little more difficult if the sock reaches all the way to his waist. Again we were able to cut the possibility of chill and colds considerably.

We devised a sleeping bag which not only keeps him warm but also ties him in bed. He is free to sleep either on his tummy or on his back.

We use canned dietetic fruits to supplement his diet and to satisfy any craving for sweets he might have. When we sweeten anything for Chris we use Sucaryl rather than sugar.

Chris sits in a youth chair at the table with the family. He eats essentially the same foods in lesser amounts and with different sauces. We have plain green beans -- Chris has butter on his.

Finally -- We have done everything but hang a sign on him "DO NOT FEED." The diet does not and cannot tolerate any deviation... the slightest snack would be disaster. Our children and our neighbors' children realize that Chris is not allowed to share in neighborhood treats. But it is worth the constant vigilance to see our child, who a short six months ago could not walk because of ataxia, run to his daddy and signal a wish to be picked up.

DIETARY TREATMENT OF GALACTOSEMIA [1]

Phyllis B. Acosta*

Recent publications indicate that dietary treatment of galactosemia with the withdrawal of lactose and galactose, in addition to being a life-saving procedure may also be a means of preventing mental retardation. (1) It appears that, in order for dietary treatment to be most effective, it should be started as near birth as possible. (1) The suggestion has also been made that better results might be achieved if the diet of the mother during gestation were restricted in lactose and galactose. (1) However, proof for such a step is presently lacking.

With the importance of dietary treatment established, it is necessary for the nutritionist or dietitian to know how to fill a prescription for a galactose-free diet. In addition, it is also important to know nutrient needs and eating habits of infants and children of various ages. The objectives of this report are to: (1) review briefly the metabolic defect in galactosemia; (2) define the method of dietary treatment used at Child Development Clinic, Children's Hospital in Los Angeles; and (3) review some nutrient needs of normal children and how these needs may be altered in galactosemia.

Metabolic Defect

Galactosemia is an hereditary disease transmitted by an autosomal recessive gene which affects the ability to metabolize galactose normally. (1) The faulty metabolism is due to a defect in the enzyme galactose-1--phosphate uridyl transferase (2) which is necessary to convert galactose-1-phosphate to glucose-1-phosphate (Figure 1). Because of this defect, galactose-1-phosphate accumulates in the body tissues and is thought to cause damage to the developing brain, liver, lens of the eye and other organ systems. (3) The accumulation and disposition of galactose-1-phosphate is of prime interest in galactosemia. Even before the specific enzyme had been discovered, Schwartz et al., showed that galactose-1-phosphate accumulated in erythrocytes of patients with galactosemia and suggested that this fact might be useful in evaluating dietary intake of galactose. (3)

The possible role of galactose-1-phosphate in pathogenesis of the symptoms of the disease is further strengthened by recognition of the in vitro inhibition of a number of enzyme systems by this substance. (4)(5) While the erythrocyte has been used as an indicator of galactose-1-phosphate content of other organ systems the final proof of such a direct relationship is still lacking; however, in one case Schwarz (6) found a reasonable correlation. In studies reported by Donnell et al, an erythrocyte content of galactose-1-phosphate of 3 mg. per cent was considered to be a safe value. (7) For the present, this level is compatible with satisfactory physical and mental development of patients as judged by clinical observations. (8) Data based upon long-term observations is needed for final proof. In the meantime, however, there is no question in our minds that this test serves as a sensitive tool for evaluating dietary galactose intake. Dietary control is monitored by performance of this test every 2 to 3 months. Alterations in diet can be readily detected by its use.

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[1] Paper prepared in cooperation with George W. Donnell, M.D., and Richard Koch, M.D.
*See Attendance Roster in Appendix for title and address.

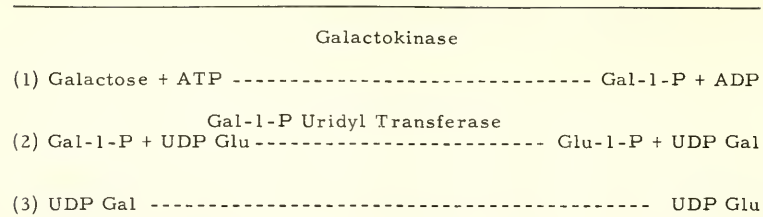

Figure 1.--Major pathway by which galactose may be converted to glucose.

Galactose-Free Diet

At the present time it is impossible to supply the missing or defective enzyme. Therefore, the only method of treatment for galactosemia is by diet. This consists of removing "all" sources of galactose. In phenylketonuria, the offending substance cannot be completely removed because it is an essential amino acid and is necessary for proper growth. While galactose is part of certain essential structures of the body, the necessary amounts can be synthesized as needed. Therefore, a galactose-"free" diet can be given without known detrimental effects.

The most important source of galactose is milk. The basis for the galactose-free diet is a milk substitute formula "free" of galactose. In our clinic, Nutramigen[2] is most commonly used. The manufacturers of this product have indicated "that Nutramigen powder will always contain less than 0.23 per cent galactose, probably about half this figure...." The substitute formula compares well with milk in nutrient content as can be seen in Table I.

The use of soya bean milk formulas has given rise to considerable controversy due to the presence of galactose-containing oligosaccharides as raffinose and stachyose. (9) Other legumes are also common sources of the oligosaccharides. It has been stated that these substances are not hydrolyzed to galactose and consequently are harmless to galactosemic patients. (10) Such reasoning is based upon the failure to demonstrate the presence of the necessary enzyme systems in the human gastrointestinal tract to hydrolyze galactose-containing oligosaccharides.

In an attempt to obtain objective evidence regarding this problem, several patients in our clinic have received supplementary feedings of soya bean products (200 gms/day) for periods of one to two weeks. Simultaneous measurements of erythrocyte galactose-1-phosphate were obtained (Figure 2). Note that the galactose-1-phosphate content did not rise above base-line values on a galactose-free diet. When small amounts of galactose-1-phosphate were added to the diet, prompt rises in erythrocyte galactose-1-phosphate values were obtained. Although the studies presented do not completely settle the issue of the suitability of feeding galactose containing oligosaccharides, these foods can be used if facilities for monitoring the erythrocyte galactose-1-phosphate content are available.

Meat, poultry, fish and eggs are excellent protein sources; however, certain galactose-storing organs such as liver, pancreas and brain must be avoided. Labels of cold

[2] Mead Johnson and Company, Evansville, Indiana.

TABLE I

COMPOSITION OF VARIOUS MILK SUBSTITUTES COMPARED WITH AVERAGE COMPOSITION OF WHOLE COW MILK[11]
(diluted to 20 calories per ounce)

COMPOSITION	WHOLE COW MILK	SOBEE	MULL-SOY LIQUID	MULL-SOY POWDER	SOYALAC LIQUID	SOYALAC POWDER	NUTRAMIGEN
Major Constituents (gm./100 ml.)							
Protein	3.3	3.2	3.1	3.1	2.05	2.85	2.2
Fat	3.7	2.6	3.6	4.0	4.00	3.20	2.6
Carbohydrate	4.8	7.7	5.2	4.5	6.00	5.40	8.5
Content of Vitamins and Minerals per quart:							
Calcium, mg.	1250	1000	1200	1240	390	813	1000
Phosphorous, mg.	960	500	800	1110	300	370	700
Sodium, mEq.	25.0	20.8	15.0	15.0	12.6	28.2	18.7
Potassium, mEq.	35.0	31.2	38.0	38.0	21.7	25.7	25.6
Iron, mg.	1.0	9.5	5.0	4.0	10.0	10.0	10.0
A, I.U.	1130	2500	2000	---	2500	---	1500
D, I.U.	400*	400	400	---	400	---	400
Ascorbic Acid, mg.	18	---	30	---	---	---	30
Niacin, mg.	0.85	3.9	7.0	3.5	1.1	1.6	4.0
B_{12}, mcg.	5.6	---	1.0	---	2.0	---	4.5
Thiamine, g.	420	380	500	80	220	360	460
Riboflavin, g.	5170	570	800	260	120	350	1800

*In milk marketed in the United States, Vitamin D is ordinarily added to insure a content of 400 I.U./qt.

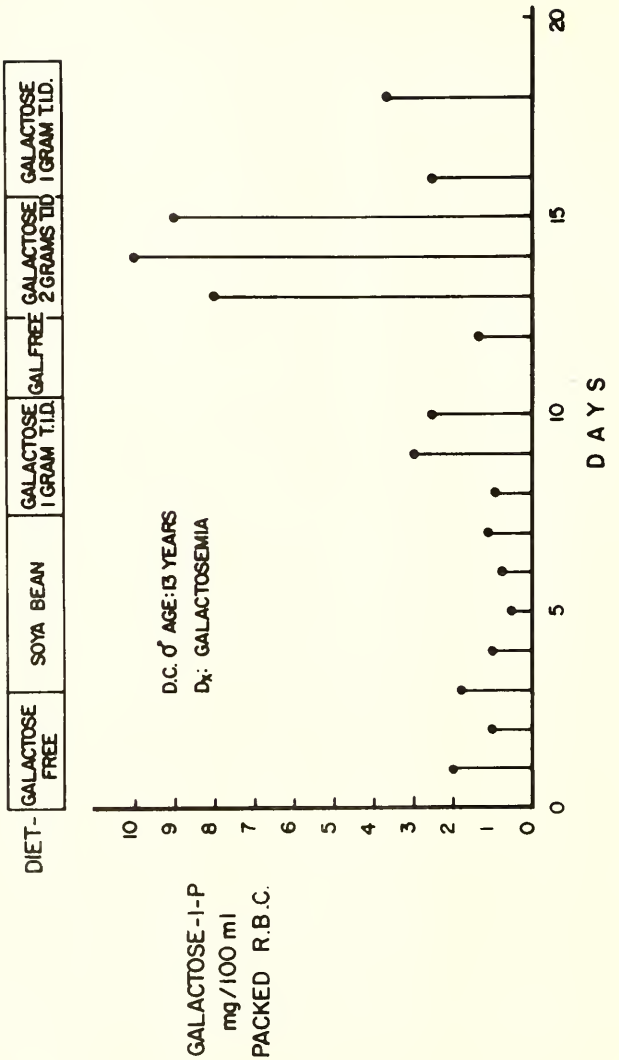

Figure 2.--Effect of supplementary feedings on erythrocyte levels of galactose-1-phosphate.

cuts and other meats commonly containing fillers should be carefully scrutinized to insure the exclusion of milk and milk products. Creamed and breaded meats, poultry and fish should also be excluded from the diet.

Most vegetables and fruits except peas, sugar beets and lima beans may be included. These vegetables contain substances which may give rise to galactose. Oils, shortenings and lard contain no galactose and are suitable for use; however, labels on margarines should be carefully scrutinized to be sure that milk in the form of whey, casein, dry milk solids, lactose or curds is not included. Again, the use of margarines containing soya beans and soya bean products is questionable, but in our clinic where the galactose-1-phosphate is determined regularly these items are allowed.

The commercial cake, pudding, cookie and pie mixtures ordinarily contain milk, lactose, or chocolate. It has been found that all cocoa and chocolate contain milk in small amounts. Carob powder, if skillfully used, is an acceptable substitute for cocoa. Homemade desserts are not a necessity in the diet. They may be used on special occasions to give the child a feeling that he is not different from others.

In the past, it has been our policy to exclude all chewing gums from the diet, based on correspondence with the William Wrigley Jr. Company. They state:

> A pellet of P. K. gum (sugar coated) contains approximately 42 mg. of Gum Arabic. Assuming complete digestion, this could possibly yield 33 mg. of galactose. One piece of our stick gum for example, Spearmint, contains approximately 18 mg. of calcium-magnesium salt of a polysaccharide. If this were completely digested it could provide slightly less than 3 mg. of galactose. (12)

Much of the same information was obtained from the Beech-Nut Life Savers Inc. (13) Gum Arabic is used in many foods commonly found on the market. Presently, with the availability of a monitoring system, we are allowing the use of chewing gum and other products containing Gum Arabic.

Table II (see supplementary date C in the Appendix) lists some of the typical uses of lactose. The wide variety of products in which lactose may be used again points up the need for careful scrutiny of labels. Manufacturers should be contacted if there is doubt concerning ingredients in any product. Table III lists foods which may be included and those which should be excluded from a galactose-free diet.

Nutrient Requirements

The nutrients required by the galactosemic child are not different from those of a normal child of similar age, height and weight. However, there are particular nutrients which must be taken into consideration at specific times. In the newly diagnosed child, other than a newborn, particular attention should be given to the caloric content of the diet. Due to the inability to utilize galactose, with a subsequent loss in the urine of galactose, protein and amino acids, the galactosemic child is usually underweight. Ordinarily, removal of galactose from the diet is followed by rapid gains in weight.

When protein and amino-aciduria have been present for a continuing period of time, proteins will be depleted and should be increased above the recommended amounts during the initial stages of treatment to compensate for losses which occurred prior to diagnosis. The major source of protein in the diet of the young infant will be from a milk substitute (Nutramigen, soya bean milk). With increasing age, the addition of solids containing meat and eggs will supply additional amounts of protein with very little calcium. If

Nutramigen is the substitute chosen, 10 to 20 measures or tablespoons of the dry powder should be used daily, depending on age, to give sufficient amounts of calcium. If a soya milk preparation is used, one containing added calcium phosphate and vitamin B_{12} should be chosen. When the substitute formulas are not well accepted, the physician may wish to give supplements of calcium.

Mothers of galactosemic children are asked to keep a three-day diet record immediately prior to their clinic visit. Specific amounts of all foods given are to be carefully recorded. The nutrients in the foods recorded are calculated by the nutritionist and the mean is compared to the National Research Council Recommended Daily Dietary Allowances. Figure 3 demonstrates the percentages of the allowances met by three children with galactosemia during a three day period in Los Angeles.

Summary and Conclusions

The importance of early diagnosis and treatment of galactosemia cannot be overstressed since delay in treatment decreases the potential mental capacity of affected children. It is the responsibility of the nutritionist and dietitian to teach the family and the child principles of the galactose-free diet as well as sound basic principles of good nutrition. When the dietitian resorts to substituting foods which contain only calories but no other nutrients, she is not filling her responsibilities.

In this report: (1) Present concepts of the basic defect in dalactosemia are reviewed and a method of monitoring dietary control is suggested; (2) a diet for galactosemia with foods that may be included and those which should be excluded is given; (3) nutrient needs with possible variations from normal needs are discussed; and (4) three-day diets of three children with galactosemia are compared with the National Research Council Recommended Daily Dietary Allowances.

Figure 3.--Percentage of NRC Recommended Dietary Allowances Met by Three Children with Galactosemia during a Three-day Period in Los Angeles 1959

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HOW NUTRITIONISTS ARE WORKING IN MENTAL RETARDATION PROGRAMS

IN A REHABILITATION UNIT

Patricia Ernest*

Much of the mental retardation work conducted by the Department of Dietetics and Nutrition of the University of Kansas Medical Center is at the Children's Rehabilitation Unit. The Unit operates on the philosophy that most handicapped children are best cared for while living at home, provided that adequate community resources are available. About one hundred children handicapped by cerebral palsy and other neuromuscular disorders, retardation, and hearing and speech problems are enrolled in day programs. The Unit serves as a laboratory for teaching, research and experience by students in many fields of endeavor: medicine, education, psychology, social work, speech therapy, occupational and physical therapy, as well as dietetics and nutrition.

Shortly after the Unit was opened in 1958, a need was felt for a school lunch program. The objectives of this program were: 1) to enable the children to have a hot, nutritionally adequate noon meal; 2) to provide an opportunity to encourage better eating habits and self-feeding techniques; and 3) to provide a clinical laboratory for students and staff, particularly in the areas of education, occupational therapy, and dietetics and nutrition. The school lunch is patronized by physically and mentally handicapped elementary and junior high school pupils. At the present time, approximately forty-five children and eight teachers participate, plus auxiliary feeding personnel. The food service is under the supervision of the dietitian affiliated with the pediatrics unit of the medical center.

Menus are similar to those used in other school lunch programs. There is, however, more emphasis on the use of easily masticated entrees and desserts. These children seem to accept mixtures more readily than do hospitalized children. Special feeding equipment is utilized as necessary. Children of all ages are offered morning and afternoon nourishments of assorted fruit juices or milk and a simple cookie or cracker. Some groups are served orange juice daily by the request of the teachers, who are aware of the financial burdens of the families, and know that ascorbic acid might otherwise be low in the child's diet.

The Children's Rehabilitation Unit provides many areas in which the dietetic graduate students and staff have opportunities for experience and research. First of all, the dietetic intern, during her pediatric service of two weeks, supervises the school lunch program, does menu planning and assists with the feeding of the children. During this period she may discuss the weekly menus and evaluate the nutritive content with the Junior High class.

One of our graduate students completed her thesis on "Food Color Preferences of Four to Eight Year Old Children." The object of the study was to determine whether sex or intellectual ability influenced the color choice. The subjects were divided into three groups. Group 1 was composed of children of average to above average intelligence in a

*See Attendance Roster in Appendix for title and address.

public grade school in Kansas City, Kansas. Group II included children in the Preschool Class for Educable Retarded Children at the Children's Rehabilitation Unit. Group III was composed of severely retarded children in residence at Parsons State Hospital at Parsons, Kansas. Each subject was asked to choose between two colors of one food product at each of thirty-six trials. Lemonade, milk and frosted graham crackers were colored blue, red, yellow and white. A difference in color preference was noted between the boys and girls. The first choice of the boys was blue whereas, the girls preferred red. The intellectual capacity of the subjects did not appear to influence color choice. The rank of color choice in descending order was blue, red, yellow and white. It is suggested from the study that including a variety of interesting colors is of value and should be taken into consideration, regardless of the mental ability of the child.

A staff member interviews mothers of preschool children with hearing disorders to study whether any different pattern of eating among these children can be defined. Her questionnaire includes a history of past and present food intake, food preferences, and feeding problems that the mother has encountered. Although the study is not yet completed, it would appear at this time that these children have much the same eating habits as the normal child. Low milk and citrus fruit intake seem prevalent, as is so often the case with the normal child.

Once a year the Junior High class of mentally retarded children visits the Food Production Unit and eats in the hospital cafeteria. The teacher and dietitian plan this tour together, discussing with the students selection and prices of food and areas which the students might particularly be interested in seeing. Our department has also been utilized in vocational guidance training with these same students. Katrina helped in the set-up and carrying of trays. In order to further evaluate her abilities, she was shifted to the hospital area where she assisted with the tray service to patients on the orthopedic children's ward. Alicia is now working in our food production area on the dish machine. She is learning speed and correlation of her motions in removing paper items from the trays on the conveyor belt. When she has mastered this, it is hoped that she can move into another area, perhaps the portion serving of desserts or salads. This type of training is valuable to the instructors of these children in ascertaining work capabilities and recommendations regarding future employment.

Counseling of the parents by a dietitian is an area in which some help has been given. However, there is much opportunity here for future work. Some children are underweight, others have a problem with obesity. The parents of the child with any feeding problem would benefit from some guidance by the dietitian. Many opportunities are available for future research, and we hope that much more can be accomplished in helping these children to a more healthful, useful, and happy life.

IN CLINICS

Elizabeth Read*

The main purpose of the Oklahoma Mental Retardation Training Center at Tulsa is to offer training opportunities to professional people interested in mental retardation. I take part in the weekly evaluation clinics along with the other members of the staff and consultants. I take diet histories on those patients whose applications gives some indication that the information would be pertinent. I give direct service to those children and parents who need it. Although we are following one patient with galactosemis and six with phenylketonuria, the majority of children are referred for nutrition counseling because they are obese, or undernourished, or need help in feeding themselves, or in related problems of managing their food.

The public health nurse on the Center's staff visits every patient's home, even in outlying areas, as well as attending clinics and staff conferences. She may seek dietary advice before she visits a home and occasionally requests that I accompany her.

At the Children's Medical Center there is a 42-bed hospital, a large out-patient department, and a child guidance clinic, as well as the Mental Retardation Training Center. On the few occasions when a child with phenylketonuria has been admitted as an in-patient, I have had informal classes for nurses, aides, and dietary personnel.

At Sunnyside School for handicapped children, those children who are able to do so prepare their own lunch under supervision. Some of the older children are taught simple kitchen tasks. Two of them have developed enough proficiency to be employed in the food service unit.

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*See Attendance Roster in Appendix for title and address.

IN FOLLOW-UP SERVICES IN THE HOME

Florence Scott*

Oregon has an extensive program of phenylketonuria detection and treatment in which the Maternal and Child Health Section nutritionist has played an active role.

Follow-up care in the home in a statewide program differs somewhat from that given by a team working closely together in a clinic. In the clinic setting the children are usually hospitalized for diagnostic tests and the low-phenylalanine diet is prescribed by the physician who understands the disease. The nutritionist or dietitian assumes her role of constructing the diet and teaching dietary management to the parents.

In the Oregon program only a few individuals came to the attention of the state nutritionist after having been diagnosed and treated initially in the hospital and then referred for follow-up care in the home. The major number came as a result of the private physician turning to the Director of the Maternal and Child Health Section of the Oregon State Board of Health for help with the testing and to the nutrition consultant for information and help before starting the diet as well as for follow-up.

Since the program began in 1959, the Maternal and Child Health Director and nutrition consultant have been working as a team to carry on an educational program with the medical and public health personnel of the state. We have spoken at state and county health and welfare meetings, at medical and nursing meetings, at the State Home for Mental Retardates, on television. At first the physicians like everyone else were relatively unfamiliar with the disease and turned to the Board of Health team for guidance in preparing the diet, as well as assistance with the low-phenylalanine formula provided by the State Health Department using Children's Bureau funds. In order to receive the assistance the phenylketonuric child must be under medical supervision, on a low-phenylalanine diet, with serum phenylalanine levels determined every three months.

Most of the diets are introduced to the home by the nutritionist. The visit is usually observed by the county public health nurse who is then able to follow through between visits by the nutritionist. Lofenalac is used exclusively to supply most of the protein. The equivalent system (1) is used to teach families how to vary the diet, which is planned to be as much like the normal diet as possible. Natural fruits, vegetables, some cereals and crackers are included to provide texture, and a variety of color and flavors. Recipes are provided, and I might add, seldom used. Careful reports of these visits are given by the nutritionist to the private physician. Blood phenylalanine levels are watched carefully as the nutritionist receives a copy of the report which is done in the state laboratory either chemically or by the Guthrie bacteriological method.

The dietary problem commonly found among phenylketonurics is lateness in starting to drink from a cup and to self-feed whether with a spoon or using finger foods. The father seems less likely to accept the situation and go along with treatment than the mother. In one case, the father of a 2-year-old boy found it difficult to eat foods not allowed in the child's diet until he learned that the child could have hard candy as a supplement.

It was soon evident that the reactions of the nurse and the mother to the diet were likely to differ. To the nurse the diet was seriously limited. The mother frequently stated

*See Attendance Roster in Appendix for title and address.

that it contained more food than her child wanted, probably more than he needed. If the patient was a young child, he had little difficulty in accepting the formula. Most of them liked it but resisted foods with texture that required the slightest chewing or were even a little bit difficult to swallow. The only children who didn't exhibit this resistance to texture were the two who were on low-phenylalanine diets from birth, having been diagnosed early because of phenylketonuric siblings.

We have also worked with some older phenylketonuric youth and young adults for whom low phenylalanine diets have been recommended to study any benefits that would accrue. We found as others have that the individual was calmer, with better motor control and better behavior if he was able to accept and continue on the diet. Only two out of five are continuing. I am not optimistic about this phase of the work.

References appear in the literature (2) that "keeping a child on a low-phenylalanine diet is easily done with initial help from the doctor" and again "that the public health nurse would do well to de-emphasize the feeding and stress other important areas as soon as feasible." Our experience tells us that while the nurse assists with counseling about many important problems, there remains always the difficult and long-term problem of staying on the diet. This problem involves more than superficial understanding of a few specifics of management. The need for guidance of parents and eventually of the child remains as long as the child has to be on the strict diet.

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Dorothy Hacker*

Education in the Well Child Conference

Offering health supervision to the mentally retarded child in the well child conference helps to emphasize to the parents and public health nurses that his food needs are the same as those of the normal child. When the Mental Retardation Center was started in New Mexico, it was anticipated that there would be many feeding problems. A review of cases at the end of a year showed the familiar problems arising from poor family diets and feeding practices that were encountered in other children.

In taking a diet history of a mentally retarded child at the conference, the parents' food problems are often uncovered. Sometimes they can be reassured as to progress; sometimes they are helped to recognize inadequacies in food intake whether caused by their own lack of knowledge, their economic situation, or the child's refusal or inability to chew or swallow. Deviations from normal are called to the clinician's attention, and following his examination, the nutritionist confers with the parents and nurse to plan for any corrections needed in the diet. If the nutritionist and nurse are not both present at the conference, they discuss the case together and plan the content of follow-up visits to the home, sometimes jointly. Contact is continued between the nutritionist and the nurse following the case.

Many parents need help on certain feeding problems. They have to learn to accept the child's actions that are representative of the level at which he is operating. They must recognize that his nutritional needs are those of a normal child and give up hope that any type of retardation will be corrected by a complicated formula with all kinds of supplements. They should realize that overindulgence prevents the child from developing as well as he can. Keeping forbidden foods out of reach has helped a child with phenylketonuria to accept a low-phenylalanine diet. Unnecessary restriction in the kinds of food offered prevents the child from learning to like a variety of foods. Parents should learn the difference between giving a child the opportunity to taste a new food with any help he may need and forcing him to eat. Consideration should be given to other members of the family who sit at the table with a severely mentally retarded child by making it as easy as possible for him to eat unobtrusively.

The nurse's home visit can help parents to recognize that progress has been made and to feel encouraged in keeping on with the slow work, taking advantage of "good days" to introduce new foods. The home visit often reminds parents of questions that they had forgotten to ask at the well child conference. It gives an opportunity to go over the educational leaflets prepared by the state for parents whose children do not chew or swallow well.

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*See Attendance Roster in Appendix for title and address.

Staff and Other Professional Education

The nutritionist has taken part recently in in-service education relating to phenylketonuria. The groups reached have been the public health staff, other nurses, and the State Dietetic Association.

Developments in the state mental retardation program have been presented to the Stat Nutrition Committee and to teachers in special education classes. Conferences have been held with Department of Public Welfare workers at crippled children's clinics regarding individual mentally retarded children.

Institutions

The nutritionist is a member of the Professional Advisory Committee to the State Hospital and School for Mentally Retarded. Consultation is given to a small private home for mentally retarded on evaluation of menus, emphasizing that improving the evening meal helps children sleep better, and encouraging the shift from a "mush mixture" to individual foods.

Individual referrals for dietary consultation are made occasionally by physicians in private practice.

IN A COUNTY HEALTH DEPARTMENT

Jeanette Pelcovits*

Prince George's County in Maryland forms a part of the Washington, D.C. metropolitan area. Although much of the county is still rural, suburban growth is marked since many of the residents work for Federal agencies in the Washington area. The county has a high birth rate and a low death rate, the preponderence of residents being young and middle-aged. Our school census now stands at around 85,000 and rises at the rate of approximately 6,000 per year. The Prince George's County Board of Education provides a special education program for trainable and educable retarded children in three training centers and in special classes held in 24 elementary and secondary schools. Currently this program serves 600 mentally retarded pupils.

Nutrition services in the health department, including promotion of nutrition education, are channeled into the elementary school system primarily through the public health nurses. We have hitherto not been directly concerned with nutritional problems in the special classes for retarded children. However, during the coming year, we expect to pay close attention to the nutritional needs of the mentally retarded pupil. We are now planning to continue to rely mainly on the public health nurse in coping with problems in this area.

Our initial effort in providing nutritional services for retarded children has been in the county recreation program. At the end of last school year we offered our services to the recreation department in its summer playground program. The recreation department has three playgrounds especially for retarded children, the first of which was started about six years ago. Last summer the enrollment in these three playgrounds totalled seventy-five for the seven-week period. Each playground is in charge of two recreation leaders, trained, educated and experienced in handling retarded children, and assisted by volunteer junior aides. The children live nearby and no transportation is provided. The facilities in adjoining schools are used for storing the lunches which the children bring from home.

For these retarded children, as for all children, the first step was to educate the parents on what to put in the lunch box. Our first move was to prepare a flyer for the children to take home to their parents, which contained suggestions and simple do's and don'ts for preparing lunch boxes. The recreation department was pleased to cooperate with us by reproducing and distributing the flyer that we prepared. This year again we plan to distribute a flyer and follow it up by periodic surveys of the lunches brought to the playgrounds for retarded children. Such a survey should be the nutritionist's responsibility since recreation leaders are busy with other activities. Based on our findings in the survey, we plan to conduct an education program for the parents, probably in the form of a nutrition workshop. In this way we hope to teach parents that while the basic nutritional needs of the mentally retarded child are the same as those of the normal child, it is particularly important that his physical vitality be kept at high peak so that he can make the most of his impaired capacities.

Apart from this modest contribution to the recreation program, the nutritionist has dealt with retarded children through direct referrals from the medical director of the Retarded and Handicapped Children's Clinic of the health department. Thus far, referrals have been limited to problems of overweight children.

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*See Attendance Roster in Appendix for title and address.

IN DAYTIME CARE CENTERS

Mayton Zickefoose*

The Delaware General Assembly of 1957 authorized the State Hospital for Mentally Ill to establish and operate community centers for the daytime care of severely mentally retarded persons for whom there are no available public school facilities. State funds are appropriated for the maintenance of these centers and for transportation, so that there is no charge to the parents of children in attendance although contributions are accepted.

The philosophy behind these centers is that handicapped individuals should remain in the community if possible rather than be hospitalized. Each child is to be helped to reach his highest potential. Parents are relieved of the care of the children during the day with resulting benefit to the family as a whole.

Under the supervision of a psychologist and two registered nurses, six centers serving a total of eighty-four children are operated by eleven training aides. These aides, socially adequate and emotionally stable women with the equivalent of a high school education, receive four to six weeks training at the Hospital for the Mentally retarded.

To be eligible for admittance, children must be four years old, have an I.Q. of less than 35, and be ambulatory except for those with cerebral palsy. The daily program stresses self-help. Good social habits, table manners, and cooperation in play are taught as well as self-feeding.

The Food Program

Food prepared by the training aides is served in the form of a hot lunch and a snack in mid-morning and mid-afternoon. Two or three cook-outs a year and an occasional buffet for the older children provide variety. Parents supply the special diets for children with phenylketonuria and diabetes. The other children are served sandwiches, soups, stews, suitably cut raw vegetables, fruits and fruit juices, milk and cocoa, ice cream and gelatin desserts.

Feeding Difficulties

Some children, usually those who haven't been taught at home, have trouble in chewing. They may have been subsisting on liquids and baby foods. Some have trouble in swallowing; they will chew or suck on solids and then spit them out. Some have had no experience in drinking from a cup or glass. Some have allergies. In general, appetite is affected when the child is not feeling well. Children who cannot talk have trouble expressing feelings of thirst.

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*See Attendance Roster in Appendix for title and address.

Feeding Accomplishments

Teaching these children to feed themselves is a long process, calling for patience and firmness on the part of the aides. Among the techniques that have been found helpful are: Standing behind the child and guiding his hand to his mouth in the normal way; wrapping the spoon with gauze, cloth or foam rubber so that it does not tip in the hand; bending the spoon handle may make it easier to grasp and get to the mouth without spilling; finger foods are more easily managed by some than those calling for a spoon; withholding dessert until other food has been eaten helps to clean plates.

Out of nineteen children who had to be fed when they were admitted to the centers, thirteen are now feeding themselves. Practically all have learned to drink from a cup or glass. Blind children learn as readily as other children. In most instances accomplishments in the center carry over into the home, but sometimes a week-end or a week's vacation can undo a lot of training. Some parents are so interested and pleased with their children's progress that they volunteer to help prepare and serve food so as to observe how the child is taught.

RESEARCH IN A CLINICAL CENTER

Phyllis B. Acosta*

The role of the nutritionist in research in general and more specifically in mental retardation programs is not well defined. That there is a need for such research cannot be doubted, particularly as one peruses nutrition and medical journals. There is a striking paucity of material on nutrition and diet of the retarded, feeding at various stages of development, and feeding problems encountered when specific conditions causing mental retardation are present.

The nutritionist ordinarily works as part of the medical team. The specific contributions she makes in planning research depend entirely on her. If she has an inquiring, perceptive mind, she will be invited to help in planning and carrying out research. My experiences have not been so much in planning large studies, but rather in directing the research of graduate students in conjunction with larger studies. I have been at liberty to pursue any aspect related to nutrition, growth, and development. It has appeared wise, once the objectives of the study and the methods to use are elucidated, to confer with the team leader for approval of the outlined procedures and possible suggestions for broadening the scope of the study.

The question: "Can a nutritionist make specific contributions which ordinarily might be omitted or less fully developed if she were not included in the study team"? can be answered with a resounding "Yes." The following example gives reasons for this answer. In a study on the effect of a low-phenylalanine diet on the behavior of older children with phenylketonuria in a hospital setting, the original study was planned without a nutritionist as part of the research team. The plan was to feed a continuous low-phenylalanine diet to the patients but at specific times to add known graded amounts of phenylalanine. The object was to see if a low-phenylalanine diet produced better behavior and if this behavior regressed with the addition of phenylalanine. When the study was completed and a dietitian calculated the diet, it was found that the hospital diet was high in protein and that the addition of the first level of phenylalanine to the low-phenylalanine diet did not increase the amount above that previously ingested on the hospital diet. In this same study, carotene-containing vegetables were given in such large quantities that carotenemia occurred in one patient and was suspected in another. If a nutritionist had been involved in the original planning, she would have been able to give the information on the hospital diet. It is also hoped that she would have used a variety of vegetables and that the diet would have been planned so as not to produce carotenemia.

A nutritionist has special skills which can make her a valuable part of a research team. The following are some general areas in which she can be most helpful:

1. Assessment of nutritional status of the group on which studies are being conducted.

2. Teaching of good nutrition principles to parents and children and assessing results of teaching.

3. Determining nutritional status of mothers of children with mental retardation of undetermined etiology.

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*See Attendance Roster in Appendix for title and address.

4. Determining nutritional status of these children whose retardation is of undetermined etiology. Tarjan in a very provocative statement says that: "During the childhood years severe nutritional deprivation, poisonings (e. g., by lead), physical injuries and infectious agents are probably the most common environmental noxae which result in mental retardation."(1)

5. Eating habits of the mentally retarded.

6. Feeding problems encountered in mentally retarded and methods used to handle these problems.

7. Balance studies on retarded in metabolic units.

Some specific areas in which nutritionists are presently making contributions may also be cited. However, in these very areas there are many unanswered questions. In connection with phenylketonuria the following questions come to mind:

1. Why do some children have less development than others under poorer control when control is based on serum phenylalanine alone?

2. What is the best level at which to maintain serum phenylalanine for overall growth and edvelopment?

3. Why are there large differences in the amount of phenylalanine that can be given to children of similar age, height, weight, and sex?

4. Why are children with phenylketonuria smaller than their normal siblings? And will the Lofenalac with added vitamin B_{12} make any differences in growth rates?

5. What are the effects on I.Q. of short term ingestion of large amounts of phenylalanine?

6. What are the most effective methods of teaching mothers in order to maintain good dietary control?

Galactosemia poses problems which, if solved, may give answers to questions in basic nutrition, such as whether there is digestion of gum Arabic and other oligosaccharides. In addition more information is needed on the effects of early dietary treatment in relation to the development of I.Q.

Leucine-induced hypogylcemia(2) also presents many unanswered questions. Presently the diet given to the small number of cases is very low in protein. In one case seen, growth and development are retarded particularly in the presence of steroids.

In the future maple-syrup urine disease(3), histidinemia(4), hyperprolinemia(5), hydroxyprolinemia(6), and perhaps many other inborn errors of metabolism associated with mental retardation will become familiar to the nutritionist. Dietary means of treating these diseases must be found. Nutrition histories should be included in examination on all mentally retarded individuals. Means of improving their nutrition should be sought. The nutritionist, as one who "knows all about food," will be consulted more frequently. The contributions she makes will be definitely her responsibility and the responsibility of those who have taught her. It is hoped that she will use her skills wisely in facing the problems presented her in preventing mental retardation.

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DISCUSSION

A question as to what was learned about previous food intakes in working with older children with phenylketonuria brought out that, in Oklahoma and Oregon, these children had above-average protein intakes and had a preference for some protein-rich foods.

Considerable discussion was stimulated by the question: "What kind of a job are we doing in follow-up and in exchanges of information between clinical centers and the community agencies?" Community nutritionists profited from a state-sponsored meeting on phenylketonuria at the Illinois Research Hospital. In one state, a community nutritionist and a dietitian have made home visits with a public health nurse. A nutritionist in one state has sent information to her counterpart in another state to which a phenylketonuric patient was moving.

Some needs that were expressed were: for better communication with the physician as to the role of the dietitian or nutritionist; and for diet therapy and community sections of dietetic associations at all levels to work more closely on all aspects of diet therapy, including mental retardation. Such cooperation is being encouraged in the current projects of the Community Nutrition Section of the American Dietetic Association.

THE PREPARATION OF NUTRITIONISTS AND DIETITIANS FOR WORK WITH MENTAL RETARDATION PROGRAMS

PRE-SERVICE TRAINING OF NUTRITIONISTS

Juanita A. Eagles, Ed. D.*

Increasing attention has been directed to the contribution of the science of nutrition in the prevention and treatment of chronic diseases and handicapping conditions. The role of the nutritionist in providing both consultation services and direct services in these areas is being recognized more widely. At this conference, we have had an illustration of the scope of nutrition services through our consideration of how nutritionists are working in mental retardation programs. Such expansion of services has indicated the need for the revision of training programs.

Statements from the American Public Health Association's Committee on Professional Education (1) Committee on Administrative Practice (2) and Food and Nutrition Section (3) were designed to guide recruitment and training of nutritionists and to outline responsibilities and functions of nutrition services. A subcommittee of the Joint Committee of the American Home Economics Association (4) and the American Dietetic Association (5) outlined areas of study in "Objectives for the Preparation of Public Health Nutritionists."

Curriculum content has been a major concern of those involved in the training of public health nutritionists. In 1950, Directors of Graduate Programs in Public Health Nutrition were invited by the Children's Bureau to Washington, D.C. for the purpose of discussing common problems. Conferences have been held annually or every two years since that time. The purpose of the Eighth Conference, held in 1962, was "to refresh thinking in regard to current philosophy, goals, problems and practices in public health, with emphasis on their implications for the field of nutrition, and, on the basis of this orientation, to evaluate curricula."(6) The course directors carefully reviewed the revised edition of "The Educational Qualifications of Nutritionists in Health Agencies"(7) and concurred with the recommendation that course credits be distributed with approximately 1/3 in nutrition, 1/3 in social welfare, community organization, behavioral sciences and education, and 1/3 in public health; and that opportunity be provided for field work. It was realized that curricula finally arrived at will allow the strengths of each institution to function unhampered by standardization so that the needs of each individual student can be met.

The accepted primary objectives of graduate education in nutrition are to help the student develop competence in nutrition, understanding of public health problems, appreciation of the role of nutrition in the solution of public health problems, and skills in the application of nutrition to these problems. The consensus is that the short length of time in training is a limitation to including many experiences of recognized value to the student.

To determine the extent of current programs in preparing nutritionists to work with mentally retarded children, the thirteen schools offering graduate training in public

*See Attendance Roster in Appendix for title and address.

health nutrition were contacted by mail. Replies were received from six, showing that the scope of present activities varies from school to school. In four schools, plans are being made in the revision of the curriculum and field experience for increasing attention to be given to the problem of mental retardation in children. In some cases, this will be possible through time spent in centers and institutions so that the nutritionist will have an opportunity to determine how she can best serve as a consultant to the public health nurse involved in home-care follow-up of the children, to gain an understanding of the ways in which she and the hospital dietitian can work together to promote optimum continuity of care, and to learn how she can make useful referrals back to the institution from the community. The current situation is indicated in the following summarized comments:

(1) A concept of value to the public health nutritionist is the continuum of nutrition in the life cycle.

(2) An introduction to the problem of mentally retarded children as individuals requiring assistance is presented to students, while emphasis is upon nutrition in the normal growth and development of individuals of all ages.

(3) Knowledge and interest in published research are fundamental to the public health nutritionist and serve as a stepping stone to the application of basic principles to special situations.

(4) Statements from the six schools regarding special activities in the area of mental retardation show that

- In two schools, the only special aspect of the problem is work with children with phenylketonuria.
- In another school, a limited amount of time is spent in schools for the deaf, for the blind and for children with cerebral palsy. This is in addition to cases encountered in home visits with public health nurses.
- In a fourth school, all students observe the care of retarded children and have courses oriented to child development. Individual students, depending on their background and need, take courses in psychology, sociology and social work which contribute to knowledge in this area.
- In a fifth school, studies are conducted in mental homes for children and adults. In addition, opportunities are provided for nutrition students to take two courses given by psychiatrists, which may give them insight into the needs of mentally disturbed or mentally retarded children, and to do special studies with psychiatrists.
- In the sixth school, a cooperative program in nutrition and in growth and development, including special problems such as mental retardation, is available for interested, qualified students.
- One course director expressed the need for more knowledge concerning methods of evaluation of growth and development of nutritional status as many students have not been exposed to this field of knowledge and research. She also expressed the need for firsthand experience by students with the feeding of normal children.

The Directors of Graduate Programs in Public Health Nutrition are aware of new frontiers opening in the field of nutrition and wish to prepare students to help solve present problems and to meet new challenges which shall arise. Considering the limited

number of graduates in public health nutrition, a total of twenty-nine in 1962 (6), concerted efforts in recruitment must be made by all concerned, whether within the training institution or the agency, so that nutritionists will be available. In-service programs must be utilized to a greater extent to supplement the training of potential nutritionists in order to cope with developing problems.

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PRE-SERVICE TRAINING OF DIETITIANS

Patricia Ernest*

The preparation of dietitians to work with mentally retarded children has been an aspect of the curriculum in dietetics that is recently receiving much attention. Pre-service education in nutritional care of the mentally retarded is developing in a diversified manner, receiving impetus as developments in research occur. A two-pronged effort in prevention and rehabilitation by workers in the pediatrics field has been a spur to the development of this education, since a need for dietitians has been identified.

The most active developments appear to be in the area of inborn errors of metabolism. The recognition of the effect of such errors on mental retardation has led to an attempt to prevent this problem, and thus to the development of special diets. In those areas where clinics for inborn dietetic interns has included service in these clinics. Some experiences with in-patients and out-patients are also provided.

This information is an example of the kind of learning experiences offered in internships. A letter was sent to nineteen internships selected from various areas of the country, asking for information covering pre-service education in nutritional care of the mentally retarded. Eighteen replies were received. Although this is an arbitrarily drawn sample, the replies summarized in the following table give some indication of the scope and kind of learning experiences offered for dietetic interns:

Learning Experiences with Mental Retardation Provided for Dietetic Interns in Eighteen Hospitals

Kind of Experience	Number of Hospitals	Comments
No Experience with Mental Retardation	5	Two included experience with emotionally disturbed children.
Class Discussion of Inborn Errors and/or Mental Retardation	8	Classes are conducted by various individuals, including pediatricians, social workers and dietitians.
Phenylketonuria Clinic	6	One study under Public Health auspices is participated in by interns.
Out-patient Mental Retardation	6	
Hospital Mental Retardation	8	Most of these experiences are on the basis of possible admittance and include experience in feeding
Field Trips	2	State schools for the mentally retarded
Home Visits	1	
Summer camp	1	
Required Readings	3	

*See Attendance Roster in Appendix for title and address.

Several hospitals provide two or more learning experiences such as class discussion, clinic and in-patient observation and feeding.

A particularly noteworthy experience is provided students at the University of Michigan. Two dietetic interns have a special affiliation with a summer camp for handicapped children. This concentrated experience includes supervision of the food service, classes on good food habits and consultation with other professional personnel on improving food habits.

The interest in phenylketonuria and other inborn errors of metabolism may be seen in the classes, clinics, bibliographies and specialized opportunities given students on these subjects. In California, the interns at Loma Linda presented a program for the Dietetic Association with a phenylketonuria theme. Students at the University of Wisconsin have an opportunity to work with a team including a doctor, medical social worker, psychologist, and dietitian in a study of seven phenylketonuric children. This experience includes calculation of food intakes, recipe development and instructions to mothers.

The Children's Rehabilitation Unit at the University of Kansas Medical Center offers a different kind of experience to the dietetic interns. The objective of the care provided is to develop the child as far as possible in the role of a useful member of society. The Rehabilitation Unit is a day school operation in which a lunch is served. This program affords an opportunity for the interns to assist in the feeding of cerebral-palsied children and to observe and assist in the service of the meal.

Experience in the Department of Dietetics and Nutrition has been given some of the more capable of the children. Alicia worked in pre-preparation and the dish-room with support from the dietitian and/or the intern on the service. Such close, direct contact helped the intern develop her understanding of mental retardation and the special educational needs of these children.

The field trip that the mentally retarded children take to the Department of Dietetics and Nutrition is used as an opportunity for the intern to eat with them and to discuss their food choices. In the elementary and preschool groups nourishments are served. This service is observed and supervised by the interns in their pediatric rotation. As in many of the other internship programs, a class on inborn errors of metabolism is included in the therapeutic class hours. While the students are on the pediatric service, discussion of the feeding of mentally retarded children is based on the experience provided in the Rehabilitation Unit. A clinic for phenyketonuria meets once a month, and experience is provided in this clinic.

It would appear that recognition of the need for dietitians trained in feeding mentally retarded children is growing. Learning experiences as listed above are varied and meaningful. The evaluation of the effect of this educational experience must be deferred until these students have an opportunity to work and make their influence felt in the field. However, as Nan Bernstein indicated in a previous conference on nutrition in relation to mental retardation, there is a need for the services of the dietitian. She found that eighty percent of the patients needed the services of the dietitian. As this need is further identified, a spur will be given the institutions which educate dietitians to provide the learning experiences necessary. With President Kennedy's obvious interest as an added incentive to the programs, it is reasonable to suppose that more institutions will provide this experience. Institutes such as this which provide an opportunity to share ideas and to take suggestions to our own areas will bring further development.

It is currently the trend in education of the future dietitian to place emphasis on the whole patient as a member of a community - family and social. Consequently, in the area of mental retardation, it is reasonable to suppose that dietitians will work with the family of the child as well as the child himself. In this context it would seem that more home visits will be included in future educational programs. As research develops, prevention will be the clue to much of the educational planning and curriculums will include the experiences necessary to understand the role of infections, prematurity, and inborn errors of metabolism. Programs in the public health field will see more emphasis on the prevention of mental retardation through better education, and the dietitian will have an important part if she can be educated to perceive her role. Rehabilitation procedures offer opportunities to the dietitian, and again, education is the key to her acceptance of her potential role.

IN-SERVICE TRAINING

Ansta Barr*

In-service training consists of planned and directed study, observation, practice and exchange of information by either full-time or part-time workers. The chief purposes of in-service training for nutritionists and dietitians in health programs for mentally retarded children are:

1. To provide opportunities for us to build on our backgrounds of knowledge and abilities in gaining new knowledge to advance our contributions to programs for mentally retarded children and their families. To increase ability to interpret to colleagues what nutritionists and dietitians can contribute to mental retardation programs.

2. To broaden our understanding of mental retardation and ability to explain this to others in our profession and the community.

3. To provide more continuity in services for the retarded individual as he grows and develops and his needs change. To improve the followthrough from the services provided by dietitians or nutritionists in clinical centers to the services to families in their homes and in community facilities.

Planning in-service training involves an assessment of what the prospective trainee already knows and her need for more knowledge. It involves also finding and using available resources. The President's Panel on Mental Retardation points out in its report: "Wherever there are good services, opportunities for professional training exist. Academic and service agencies can gain much from intermeshing their resources .... for training."

Some specific ways in which in-service training objectives are being met are the following:

A. Nutritionists and Dietitians Learn from Each Other

1. Nutritionists and dietitians working in mental retardation programs are sharing information and experiences through institutes, workshops and individual contacts at the local level. When workers in clinical centers and in local health departments have regular conferences that are carefully planned and focussed, they learn a great deal from each other about such topics as interagency referral of information and recording of data meaningful in providing follow-up services. By studying the written plan of a mental retardation project and discussing it with program directors, a clearer understanding can be gained of its organization and its operation in the geographic area served. Nutritionists and dietitians aslo learn the administrative and working relationships of staff in state and local health departments and in the clinical centers. Such mutual understanding is much needed.

2. Nutritionists and dietitians are profiting by observing each other at work and by making visits to institutions and other group care facilities for mentally retarded children. The nutritionist in the health department sees how the nutritionist in the clinical center, as a member of the clinical team, works with the patient, and how she works with the public health nurse in relation to follow-up care in the home. The nutritionist in the clinical center sees how the nutrition consultant in the health department works with

*See Attendance Roster in Appendix for title and address.

the other public health staff in maternity clinics, child health conferences, crippled children's clinics, home care services by nurses, consultation to child care centers, and related maternal and child health activities. Both clinical and public health nutritionists learn from visiting group care facilities for children. Dietitians in institutions for the mentally retarded should have the opportunity to observe clinic and public health nutritionists at work. They should also have a chance to plan and take part in in-service training programs.

3. Nutritionists and dietitians are establishing an organized exchange of informational material and such teaching tools as pamphlets and visual aids. It is helpful to discuss together how to use these materials.

4. Nutritionists and dietitians are working together on common problems. For example, one group has collected information on cost to families of the diet for phenylketonuria and has compiled information on food combinations and recipes.

B. Nutritionists and Dietitians Learn from Others

1. Conferences with agency representatives provide information about community programs such as: Special schools for the mentally retarded; special education programs in public schools and the relationship of school lunch programs; sheltered workshops; foster care and group care programs; child development centers for exceptional children in university settings. Observations can be planned to give an overview of these programs and understanding of their interrelationships.

2. Nutritionists and dietitians learn from observations and conferences with the other professional members of the interdisciplinary team of the clinical center. In 1961 a one-week special course for nutritionists and dietitians working in mental retardation programs in the area included in Region VII of the Children's Bureau was conducted by the Oklahoma Mental Retardation Training Center. In evaluating the course, the group rated highly the time spent with the occupatonial therapist and suggested that they would have liked even more opportunity to observe her and the physical therapist working with children in relation to readiness for self-feeding. The most highly rated experience in this course was observing the clinical team carry out the diagnostic work-up with several patients, followed by the evaluation conference with the family and the case conference by the staff. These observations conveyed significant technical content and illustrated methods of providing service. When the trainees were asked to list in the evaluation outlines other types of workers in their general professional field who would profit from short-term courses in mental retardation, they suggested:

> Any nutritionist or dietitian working in maternal and child health or crippled children's programs; dietitians and nutritionists in other agencies serving institutions for the retarded; pediatric dietitians; home economics faculty training college and university students in child care and development; state supervisors of home economics concerned with special education and adult education programs; supervisors of school lunch programs in relation to providing lunches to meet nutritional needs of exceptional children; state extension specialists in family life, child development, nutrition, and community health.

Future Planning

Can what is learned in in-service training in mental retardation be related more closely to other phases of work with mothers and children, - in day care, institutional care, crippled children's services? In future planning for in-service training, time might well be devoted to exploring these relationships on a case basis.

We should give high priority to following up what we have gained from this institute as we go back home. We can keep informed on research findings and their application to services for patients and on state and national legislation which will influence program development. Studying the report of the President's Panel on Mental Retardation will reveal ways of implementing the proposed program for national action to combat mental retardation. State and local conferences for studying this report are already being held.

There is need for increased emphasis on services to prevent mental retardation, such as adequate maternal care before and during birth and postnatal care of mother and child. The prevalence of mental retardation is higher in population groups in which maternity care is inadequate, notably among the lower income groups in both urban and rural communities. We need to analyze what we are already doing in this important area of service and relate it to mental retardation. We need to increase the extent and effectiveness of our participation in programs for maternal and infant care. It seems probable that we will have such an opportunity. Will we take action?

SUMMARY

Mary Egan*

Five ideas permeated many of the presentations and discussions:

1. It is important to consider the child with a handicap first as a child with all the usual needs of children for love, acceptance, understanding, opportunity to develop. Such consideration will be reflected in efforts to minimize the deprivation in the growth experience and to meet the nutritional needs of the child in spite of dietary modifications. The concept will even influence terminology. For example we will say "A child with mongolism" not "A mongoloid."

2. It was re-emphasized that the child with a handicap comes from a family, a home, and a community. Economic, cultural, social and emotional factors need to be considered together with resources. Working relationships between all forces involved should be developed and coordinated so that a sound and effective plan of treatment and follow-up results.

3. Treating a child with a handicap, or more often multiple handicaps, requires an individual approach. Public health workers, accustomed to focus on the mass and the community, may need to re-adjust their thinking a bit.

4. Nutrition and diet of the child with a handicap need to be kept in proper perspective. They are only one aspect of his life and it is important to consider all aspects.

5. The nutritionist and the dietitian have a responsibility to make themselves and their services known to each other, to directors and administrators of programs, to key community groups such as State Associations for Retarded Children, and to co-workers from other disciplines.

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*See Attendance Roster in Appendix for title and address.

A LOOK TO THE FUTURE

Mary Egan*

The future of nutrition services in mental retardation programs may be affected by developments along several lines:

1. Legislation

If favorable action should be taken by the Congress on a bill to amend the maternal and child health and crippled children's titles of the Social Security Act, increased funds would be authorized for grants-in-aid from the Children's Bureau for research, training, services and other activities relating to prevention and treatment of mental retardation. The additional money would make possible the extension to more mothers and children of existing services; the development of new services; the training of workers to carry on these services; the creation of new facilities, and research.

2. Services

a. Placing emphasis on prevention of mental retardation has implications for nutrition work. Inadequate diets are likely to be associated with lack of prenatal care; lack of prenatal care may lead to prematurity; mental retardation is more prevalent in premature infants than in those born at term.

b. Greater recognition of the interrelationship between maternal and child health, crippled children's services and services to the mentally retarded should provide the opportunity for nutritionists already working in the longer-established programs to play more of a role in combatting mental retardation.

c. The increase in the types of group care facilities that are being developed to serve the mentally retarded, carries implications for nutrition consultation. These new facilities include sheltered workshops, day care centers and nursery schools, recreation centers, schools and special education classes.

d. More workers and different kinds of workers will be available to serve in programs for the retarded. Nutritionists and dietitians may be concerned with training programs for them. For example, under the Manpower Training and Development Act, there may be courses for homemaker service workers, whose future activities might include service to a home because a woman is suffering from complications of pregnancy or there is a mentally retarded child who requires intensive care. Under this same Manpower program, courses may be given for food service workers, who might find employment in day care centers or other group care facilities serving mentally retarded children.

3. Training

Training of nutritionists and dietitians is likely to be characterized by closer association with other disciplines. Opportunities will be provided for observation and experience in both clinical centers and public health programs, with the dietitian going into the community and the nutritionist into the hospital or clinical center. Opportunities should be provided for further training in diet therapy in relation to metabolic research, in methods for rehabilitation of the handicapped, and in research methodology.

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*See Attendance Roster in Appendix for title and address.

4. Research

A prospective shift in emphasis in research on mental retardation from detection, diagnosis and etiology to management, should mean that nutritionists and dietitians have a unique contribution to make toward the solution of practical problems. The findings from such applied research will undoubtedly point out the need for some changes in services for the mentally retarded. If additional funds should be forthcoming as a result of federal legislation, it is possible that money may be earmarked for demonstrations in combating mental retardation as a part of special projects in maternal and child health and crippled children's programs.

Credit for the success of the institute rests with the cosponsors, the participants in the program sessions and the resource people in the discussion groups, the various committees on program, arrangements and recording, and, finally, with the individual participants and the administrators who made it possible for them to attend. Hopefully, the three-day program has had at least four accomplishments:

1. Provided some new information and increased understanding of nutrition in relation to mental retardation through building on our foundation of training and experience.

2. Reenforced our awareness of the interdependence of the many disciplines involved in services to the mentally retarded and of the need for sharing and exchange between all concerned.

3. Encouraged us to consider the many opportunities available to enrich and enhance our background and experience in working with children with handicaps.

4. Opened new vistas and stimulated our thinking about ways to improve, strengthen and extend nutrition services to the mentally retarded, wherever they may be.

The Children's Bureau will welcome your comments, requests and suggestions prompted by this institute.

APPENDIX

SUPPLEMENT TO BIOCHEMICAL DISORDERS RESPONDING TO DIETARY THERAPY, STANLEY W. WRIGHT, M.D.

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Phenylketonuria

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SUPPLEMENT TO PHENYLKETONURIA--BIOCHEMICAL MONITORING OF TREATMENT, HELEN K. BERRY

"Use of Micro-method for serum phenylalanine in management of phenylketonuric patients"

From: Clinical Chemistry 8: 172 (April) 1962.

Equipment

Micro-hematocrit tubes, 7.5 x 50 mm.
Sealing compound or clay
Centrifuge
Micropipettes, 5, 50, 100, 200, 400 microliter
Centrifuge tubes, 2 ml.
Pipette jar of chromatography jar (6-to 10 in. diameter and 12-18 in. high) with glass plate for cover
Butyl alcohol, technical or reagent grade
Ethyl alcohol, 95%
Whatman No. 1 filter paper "For Chromatography", cut to size 7 x 11 in.
Ninhydrin (triketohydrindine hydrate)
Phenylalanine, Chromatographically Pure

Solutions

Solvent: (freshly prepared each time before using) 70 ml butyl alcohol, 20 ml 95% ethyl alcohol, 20 ml distilled water
Reagent: 0.200 g ninhydrin dissolved in water-saturated butyl alcohol
Standard solutions of phenylalanine:(A) Dissolve 20 mg phenylalanine in 50 ml water - 0.4 mg/ml;(B) Dilute 5 ml of Solution A with distilled water to 10 ml in volumetric flask - 0.2 mg/ml;(C) Dilute 2.5 ml of solution A to 10 ml in volumetric flask - 0.1 mg/ml

Procedure

Obtain blood from finger or heel puncture
Fill 6 or 8 micro-hematocrit tubes approximately 2/3 full
Seal with sealing compound. (Both ends should be sealed if specimen is mailed)
Centrifuge to separate cells and serum or plasma
Score glass tube with file just above cell layer; snapp off portion of tube containing serum and measure directly into a graduated 100 microliter pipette. Usually 0.100 ml (100 microliters) can be obtained from 6 hematocrit tubes. Note volume of serum. Measure exactly 4 volumes of 95% ethyl alcohol into 2 ml conical centrifuge tube. Add serum and mix thoroughly. For 100 microliters serum use 0.400 ml ethyl alcohol; for 50 microliters serum, use 0.200 ml ethyl alcohol. Chill for 20 minutes to complete precipitation of protein. Centrifuge to pack precipitate into tip. Supernatant is used directly to prepare chromatogram.

Mark spots 2 cm apart at bottom of sheet of filter paper (along long edge)
Apply ethanolic filtrate to spots in increments of 5 microliters until 50 and 100 microliters are applied. Dry thoroughly between applications using heat from hair dryer; initial spot size should be kept small.

To adjacent spots apply 5 microliters of each standard solution, A, B, and C. Thus spot from solution A contains 2.0 microgram phenylalanine; from solution B, 1.0 ug phenylalanine; from solution C, 0.5 ug phenylalanine.

Place solvent in chromatography jar. Staple chromatogram in form of cylinder so that edges do not quite touch. Stand upright in solvent mixture. Cover with glass plate. Resolution is complete in 4 - 6 hours. Remove chromatogram and dry off solvent. Spray with ninhydrin solution. Heat 10 min. at 90-100°C. Phenylalanine forms a blue spot about 3 1/2 in. from point of application. (Leucine gives a purple spot higher than phenylalanine). Quantitative determination is made by comparison of readings made on Photovolt Densitometer of known amounts of phenylalanine in standard spots and unknown amount of phenylalanine in blood specimen. Approximate concentration can be obtained by visual comparison.

Calculations

Serum is diluted 5-fold with ethyl alcohol. 50 microliters of ethanolic filtrate is equivalent to 10 microliters (0.01 ml) serum and 100 microliters to 20 microliters (0.02 ml) serum. If 50 microliter filtrate spot matches with the 2.0 microgram (0.002 mg) phenylalanine standard, then the concentration of phenylalanine in the specimen is 0.2 mg/ml or 20 mg/100 ml. If 100 microliter filtrate spot matches with the 0.5 microgram phenylalanine standard, concentration of phenylalanine in serum is 2.5 mg/100 ml.

Urinary phenylalanine and orthohydroxyphenylacetic acid measured in specimens obtained using filter paper

Adapted from: Helen K. Berry, Procedures for testing urine specimens dried on filter paper. Clinical Chemistry 5: 603 (December) 1959.

To obtain urine specimen

Place small piece of Whatman No. 1 filter paper (about 2 x 3 in.) inside fold of diaper (or dip in freshly collected urine). When paper is wet with urine, remove it, dry, and mail to laboratory for testing.

Preparation of chromatogram (see reference cited above)

Cut a strip of standard size from the dry urine specimen, using a pattern to ensure reproducibility. A strip 2 in. x 1/2 in. with 1/4 in. removed at each side of one end to form a blunt point contains approximately 40 microliters of urine (1.0 sq. in. of Whatman No. 1 paper holds about 45 microliters urine). A blank paper wick is placed between two glass slides and the urine strip placed at the end of the wide. The slides are held together

with clips (hair clips are satisfactory) and placed in a small beaker filled with water. Water rises up the paper wick between the glass slides, onto the urine paper, and the urine is transferred to a chromatogram. Care should be taken to keep the spot size small, 7 to 8 mm diameter. Two or three applications are usually necessary for quantitative transfer of urine from the original specimen to the chromatogram.

Chromatogram for urine phenylalanine

Mark spots on sheet of Whatman No. 1 filter paper 18 x 11 in. (along long edge). Transfer urine to chromatogram as described above. Spots should be 3 cm apart, placed 2.5 cm from edge of sheet. On spots adjacent to urine specimen place phenylalanine standard solutions: 5 microliters of solution B (containing 1.0 ug phenylalanine): 5 microliters of solution A, and on the same spot, after drying, 5 microliters of solution C (containing a total of 2.5 ug phenylalanine): and 10 microliters of solution A (5 microliters at a time) (containing 4.0 ug phenylalanine.)

Solvent for urine phenylalanine: butyl alcohol, 80 ml; glacial acid, 20 ml; water, 20 ml (freshly prepared each time before use). The chromatogram is formed into a cylinder, upright in solvent and allowed to remain overnight. The longer overnight run in the solvent (total of 11 inches from bottom of sheet) is necessary to prevent interference from urea. Drying, developing and quantitative determination is as described for serum phenylalanine.

Consistent concentration of phenylalanine in the urine from strip of the dimensions described less than 1.0 ug may be indicative of phenylalanine deficiency. Consistent concentration more than 2.5 ug in the specimen prepared as described usually indicates either excessive phenylalanine intake or illness.

Chromatogram for urine orthohydroxyphenylacetic acid (O-OHPA)

Chromatogram of same dimensions as for urine phenylalanine is used (18 x 11 in.) Preparation of chromatogram is as described above. Apply standards of orthohydroxyphenylacetic acid, 0.5 ug, 1.0, 2.5, and 5.0 ug., each on separate spots.

Solvent for orthohydroxyphenylacetic acid: isopropyl alcohol, 80 ml; concentrated ammonium hydroxide, 10 ml; water, 10 ml. (may be used for 24 - 48 hours).

Reagent for orthohydroxyphenylacetic acid (O-OHPA)

Dissolve 4.5 g sulfanilic acid in 50 ml concentrated hydrochloric acid and 100 ml water with heating. Dilute to 500 ml with water. This solution is stable indefinitely. Just prior to use prepare diazotized sulfanilic acid as follows: Dissolve 2.2 g sodium nitrite in 50 ml water; chill in ice bath. Chill 50 ml of sulfanilic acid solution. Combine sodium nitrite and sulfanilic acid and chill in ice bath at least 15 minutes to complete reaction. Immediately before spraying: combine equal volumes of cold 10% potassium carbonate and diazotized sulfanilic acid and use immediately. (Caution: phenol in atmosphere ruins chromatograms).

The chromatogram of urine and standard O-OHPA is placed in isopropanol-ammonia-water solvent for overnight resolution. After removal of solvent the chromatogram is sprayed with the reagent described above. Orthohydroxyphenylacetic acid appears as a red-orange spot against a yellow background about 7 in from the origin (Rf. 70).

O-OHPA is not detected in urine specimens from children under good dietary control. It may appear during an illness, and usually warns that serum phenylalanine levels are over 8 mg%.

1. Lofenalac

Made from specially processed casein hydrolysate,[1] corn oil, Dextri-Maltose brand carbohydrate modifier (maltose and dextrins derived from enzymic action of barley malt on corn flour), arrowroot starch, sucrose, amino acids,[2] minerals[3] and vitamins.[4]

1. An enzymic digest of casein containing amino acids and small peptides, processed to remove most of the phenylalanine.
2. OL-methionine, L-tryptophan and L-tyrosine.
3. Calcium gluconate, monobasic potassium phosphate, dibasic potassium phosphate, calcium hydroxide, potassium chloride, magnesium oxide and ferrous sulfate.
4. Each quart of Lofenalac formula of normal dilution (20 calories per fluid ounce) supplies the following vitamins:

Vitamin A palmitate	1500 units*	Pyridoxine hydrochloride	0.5 mg
Vitamin D (calciferol)	400 units*	Calcium pantothenate	3.2 mg
Vitamin D	5 units**	Vitamin B_{12}	4.5 mcg
Ascorbic Acid (C)	30 mg	Folic acid	0.05 mg
Thiamine hydrochloride	0.46 mg	Biotin	0.03 mg
Riboflavin	1.8 mg	Choline chloride	150 mg
Niacinamide	4.0 mg		

*U.S.P. **International

Approximate Analysis

		Powder (W/W)	Normal Dilution (W/V)
Total nitrogen (equivalent to approximately 15% protein)		2.4%	0.36%
Fat		18	2.7
Carbohydrate		57	8.5
Minerals (ash)		5	0.75
Including			
Calcium	0.65%	0.1%	
Phosphorus	0.5	0.07	
Iron	0.01	0.0015	
Moisture		2	86

Phenylalanine content of Lofenalac powder is not more than 0.1% nor less than 0.06%.

Measuring scoop enclosed. 1 packed level measuring scoop of Lofenalac powder supplies 43 calories. Each 100 Gm. supplies 460 calories. One 8 fl. oz. measuring cup of powder (150 grams) supplies 690 calories and approximately 120 mg phenylalanine

Mead Johnson Laboratories
Evansville 21, Indiana

2. Initiation of a Low Phenylalanine Diet
Example: Infant, Eight pounds

Day		Phenylalanine mg.*	Serum Phenylalanine mg.%
1/2	9 oz. Lo formula 1 tsp. Lo paste		45
1	19 oz. Lo formula 1 T. Lo paste 1/2 oz. milk water	25	25
2	20 oz. Lo formula 1 T. Lo paste 1/2 oz. milk	25	10
3	22 oz. Lo formula 1 T. Lo paste 1 oz. milk 1 T. rice cereal	50 6.7 56.7	4.3
4	23 oz. Lo formula 2 T. Lo paste 1 oz. milk 1 T. rice cereal	50 6.7 56.7	
5	" " (18 oz. formula)		2.7
6	19 oz. Lo formula 2 T. paste 2 oz. milk 1 T. rice cereal	100 6.7 106.7	
7	20 oz. Lo formula 2 T. Lo paste 1 T. rice cereal 2 oz. milk 1 T. str. peas	6.7 100 30.7 137.4	
8	" " (21 oz. formula)		
9	" " (20 oz. formula)		1.8
10	22 1/2 oz. Lo formula 2 T Lo paste 2 T rice cereal 1 T orange juice 1 T str. peas 2 oz. milk	13.5 3.6 30.7 100 147.8	
11	" "		
12	" "		
13	" "		2.6

Day		Phenylalanine mg.*	Serum Phenylalanine mg.%
14	23 oz. Lo formula		
	2 T Lo paste		
	2 T orange juice	7.2	
	2 T green beans	20	
	2 T rice cereal	13.4	
	2 oz. milk	100	
		140.6	
15	" "		
16	" "		
17	" "		
18	" "		
			1.4

etc. (chronological progression of diet summarized on composite graph, Appendix (8))

*Calculations do not include phenylalanine from Lofenalac sources.

Average daily intake during above period yields approximately 75 mg.

Phenylketonuria - Dietary Data

3 & 4 (Part 1)

Name: _____

Date	Age	Dietary Changes	Lofenalac		Other Foods		Daily Total Intake	
			Calories	Phenyl-alanine mg	Calories	Phenyl-alanine mg	Calories	Phenyl-alanine mg

FROM: THE CHILDREN'S HOSPITAL RESEARCH FOUNDATION, CINCINNATI, OHIO

Phenylketonuria -- Biochemical Data

3 & 4 (Part 2)

Name:_____

Date	Serum Phenylalanine mg/100 ml	Urine Phenylalanine, ug/mg creatinine	Urine Orthohydroxy-phenylacetic acid ug/mg creatinine	Weight	Height

FROM: The Children's Hospital Research Foundation, Cincinnati, Ohio

5. Diet Dairy - PKU (kept by parents)

Children's Hospital Research Foundation, Cincinnati, Ohio

Date: _____ Age: _____ Name: _____

Meal	NATURAL FOODS				LOFENALAC			
	Kind (Str, Jr, raw, etc.)	Amount eaten Level T, etc.	Protein g	Calories	Paste level T	Formula oz.	Protein g	Calories
B								
L								
D								
Other								

SUBTOTALS: DAY'S TOTALS;

PHENYLALANINE: _____ _____ _____

PROTEIN: _____ _____ _____

CALORIES: _____ _____

FLUIDS: Water_____Other_____ _____

Remarks: (appetite, eating abilities, illness, medications, supplements, urine specimen, etc.)

FORM PKU-4

6. PKU Diet Prescription Record
Children's Hospital Research Foundation
Cincinnati 29, Ohio

Date	Lofenalac			Food Additions	Total/day
	Total/day	Formula	Paste		

(Please bring with each return visit) PKU-5

7. References

Publications

1. Barbara Umbarger. "Phenylketonuria - Treating the Disease and Feeding the Child." Am. J. Dis. Children, 100: 908-913 (December) 1960.

2. Helen K. Berry, Betty S. Sutherland, George M. Guest, and Josef Warkany. "Simple Method for Detection of Phenylketonuria." J. A. M. A. 167: 2189-2190, (Aug. 30) 1958.

3. Berry, H. K. "Procedures for Testing Urine Specimens Dried on Filter Paper." Clin. Chem. 5: 603-608, 1959.

4. George M. Guest, Helen K. Berry, and Jack Rubinstein. "Newborn Siblings in Families Known to Have Hereditary Disorders." J. A. M. A. 181: 439-440, (Aug. 4) 1962.

5. Helen K. Berry. "Use of Micromethod for Phenylalanine in Management of Phenylketonuric Patients." Clin. Chem. 8: 173-173, (April) 1962.

6. Carolyn Scheel and Helen K. Berry. "Comparison of Serum Phenylalanine Levels with Growth in Guthrie's Inhibition Assay in Newborn Infants." J. Pediatrics 61: 610-616 (October) 1962.

7. Willard R. Centerwall, Helen K. Berry and L. I. Woolf. Chap. 7, "Detection" in Phenylketonuria, Frank L. Lyman, Editor, Charles C. Thomas, Springfield, Ill, 1963, pp 114-135.

Unpublished material distributed at session on March 21, 1963.

1. Detection of Phenylketonuria, Cincinnati Program

2. Urine test kit in prepaid envelope

3. Is your baby the one in every 10,000 who has PKU?

4. Detection of Phenylketonuria - Rapid Urine Tests

5. Detection of Phenylketonuria - A Proposal for a State or Regional Program

6. Phenylketonuria

7. Feeding Abilities and Characteristics (see 7a)

NAME:_____

7A.--FEEDING ABILITIES AND CHARACTERISTICS

Birth Date_____

Birth	1	2	3
Total body response			
Rooting reflex			
Sucking reflex			
Swallowing reflex			
Retrusion reflex *-10-14w			
Tearless hunger cry			
Reverse peristalsis			
2 - 4 Weeks			
Face brightens on satiety			
4 Weeks			
Looks at mother's face			
Tonic neck reflex pos. of head			
2 night feedings *-8 w			
8 Weeks 1 night feedg. *28 w			
12 - 16 Weeks			
Choking response to solids			
16 Weeks Head erect			
Anticipates on sight of food			
Arms activate at toys or food			
Mouth poises for nipple			
Some ability to wait for food			
16 - 20 Weeks Tongue projects after spoon is removed			
16 - 24 Weeks			
brings hand to mouth			
Ejects food with tongue			
Strong hand-to-mouth response as spoon or nipple is removed			
20 Weeks			
Pats bottle or breast *-36 w			
Closes in on bottle w/both hands			
Scratches table top or flat surface			

20 - 26 Weeks Grasps and draws bottle to mouth w/ assist. but releases when nipple is inserted in mouth	1	2	3
Grasps spoon			
22 Weeks Smacking noises w/lips			
24 - 30 Weeks Lower mandible in chewing pos.			
28 Weeks Sits leaning fwd.			
Takes solids well			
Feet to mouth *-36 w			
Helps bring spoon to mouth, fingers curl ard. handle, bangs, drops spoon			
Grasps spoon, nipple, cup rim			
Removes food quickly fr. spoon			
On satiety, shuts lips			
Lingers over food for companionship			
28 - 36 Weeks Vocalizes eagerness during feeding prep.			
30 - 36 Weeks Feeds self cracker			
32 Weeks Reaches toward dish			
Chokes easily drinking fr. cup			
Bites, chews toys *-18 m			
Bites, chews chicken bone			
Acquiring sitting balance			
36 Weeks Holds feeding bottle			
Feeds self cracker well			
Prehends, scissors grasp *-40w			
40 Weeks Sits well, creeps			
Combines 2 toys, utensils			
Chooses pellet, finger food			
Importance of mouth as primary sensory organ diminishing			

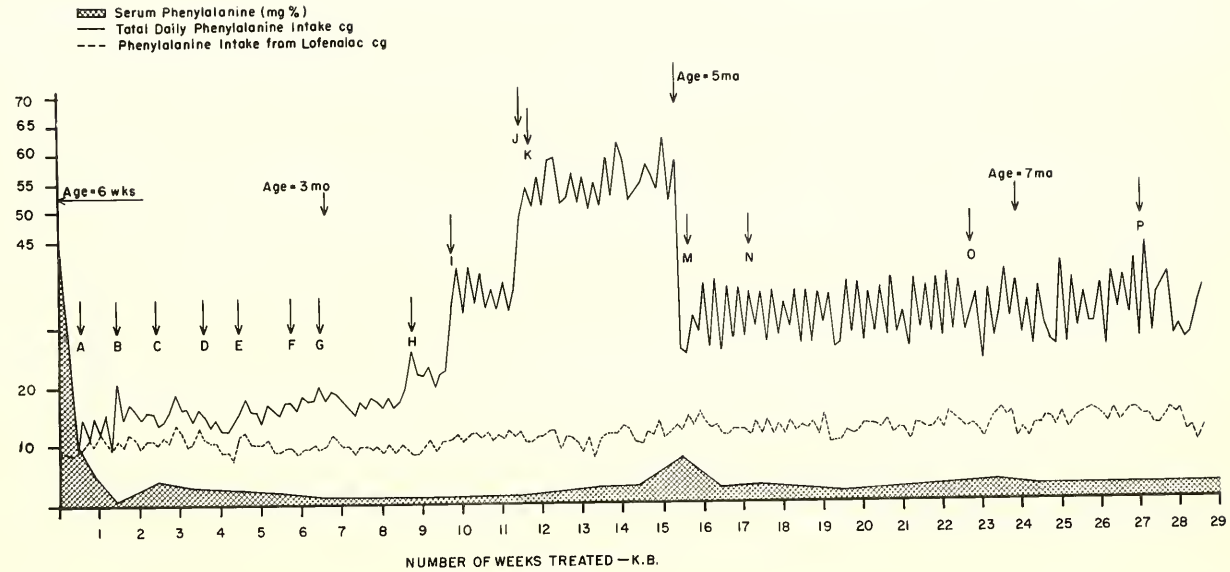
42 - 46 Weeks	1	2	3
Tries to feed self			
Drinks from cup (in part)			
46 - 50 Weeks			
Tries to use spoon			
Neat pincer grasp			
50 - 54 Weeks			
More choosy about food			
12 - 24 Months			
Bites mother's face			
Releases finger food into cup Casting			
13 - 18 Months Shakes Head "No"			
"Scrapes" tray and floor			
Hands dish or cup to mother			
Demands to help feed self			
Grasps cup w/both hands			
Grasp inhibition			
Dumps cup			
Uses spoon upside down			
Bottle discarded			
18 - 20 Months Feeds self in part, spills *-36 mos.			
Finger feeds w/pieces of food			
Lowers cup to tray well			
18 - 21 Months Spoon to mouth right side up			
Handles cup well			
Verbalizes "Eat", "All Gone", Asks for food			
2 Years Feeds doll			
Fond of ritual			
3 Years Spills little			
Pours well from small pitcher			
Feeds self well using utensils			

*extended time.

Date of test: 1: 2: 3:

THE CHILDREN'S HOSPITAL RESEARCH FOUNDATION

B. Umbarger



8. Composite Graph. See explanation on following page.

8A. Legend - Composite Graph

Hatched line-serum phenylalanine levels

2nd line - phenylalanine intake from Lofenalac, formula and paste

3rd line - phenylalanine intake from natural food additions

Entire area beneath curve - total phenylalanine intake per day, depicted in centigrams (mg/10)

A - natural protein source added (1 oz. milk). Serum phenylalanine continues to fall, going below 1 mg%, a deficiency level

B - & C - Additional protein; Lofenalac paste as a transition to solids. Water intake watched.

D - Child accepting strained vegetable and fruit in very small amounts, protein intake was sufficient to maintain satisfactory serum level for one week

E - & F - Increase in strained foods, plus fruit juice, milk, strained cereal

G - amounts of strained foods increased slightly. There was weight gain, no vomiting, lethargy or food refusals occurred; however, serum phenylalanine levels hovered in low range

H - half strained egg yolk added every other day

I - milk increased to 3 oz in addition to other strained foods

J - child required a still more concentrated source of protein

K - 2-3 tsp. liver or strained beef offered on days alternating with egg yolk plus other

L - strained infant foods as capacity allowed

M - concentrated sources of protein no longer necessary phenylalanine excess shown here, child's appetite excellent, Lofenalac paste increased, additional fluids, "Junior" and mashed table foods added for texture and fiber change

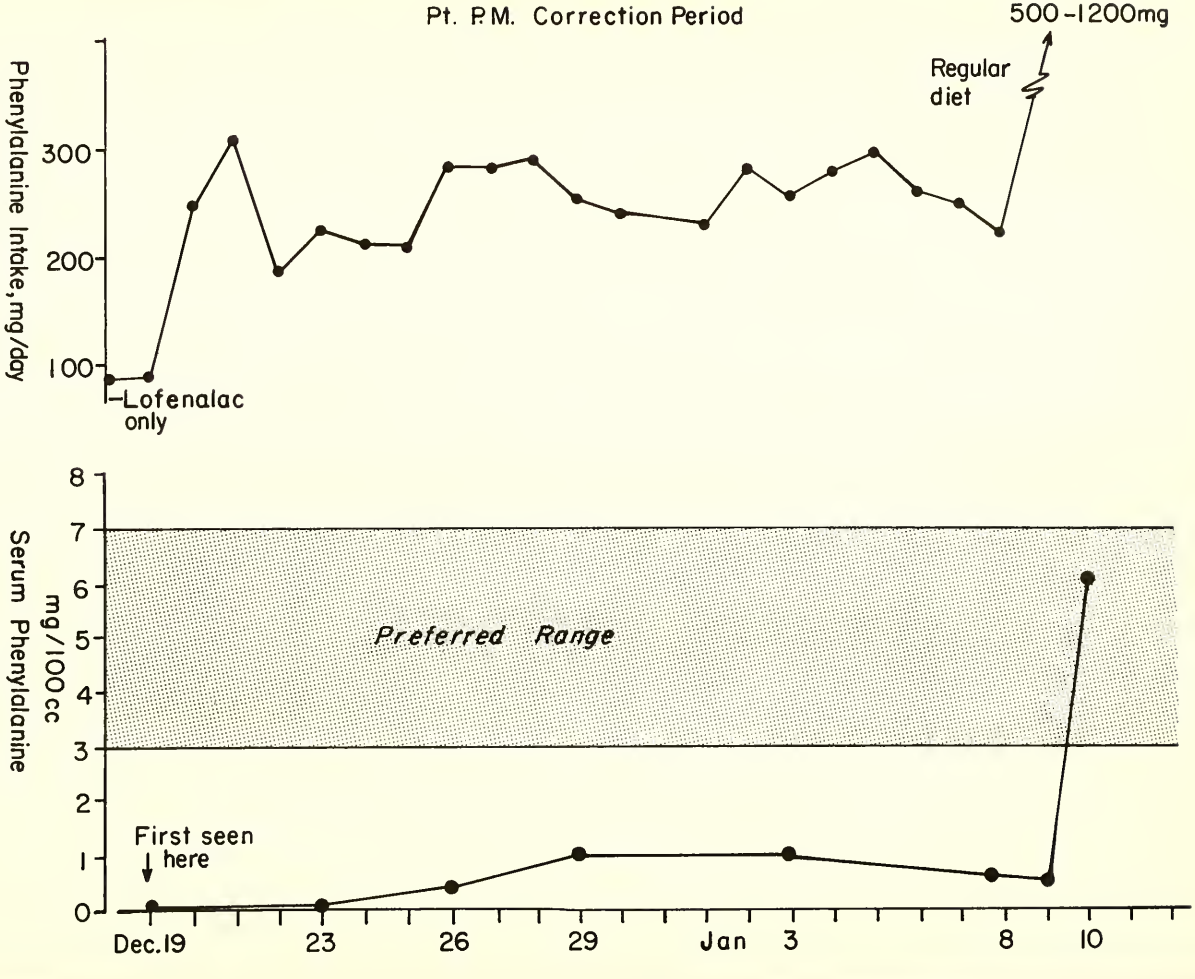
N - coarser foods, teething biscuits for added interest and chewing stimulation Serum phenylalanine levels continuing in safe range

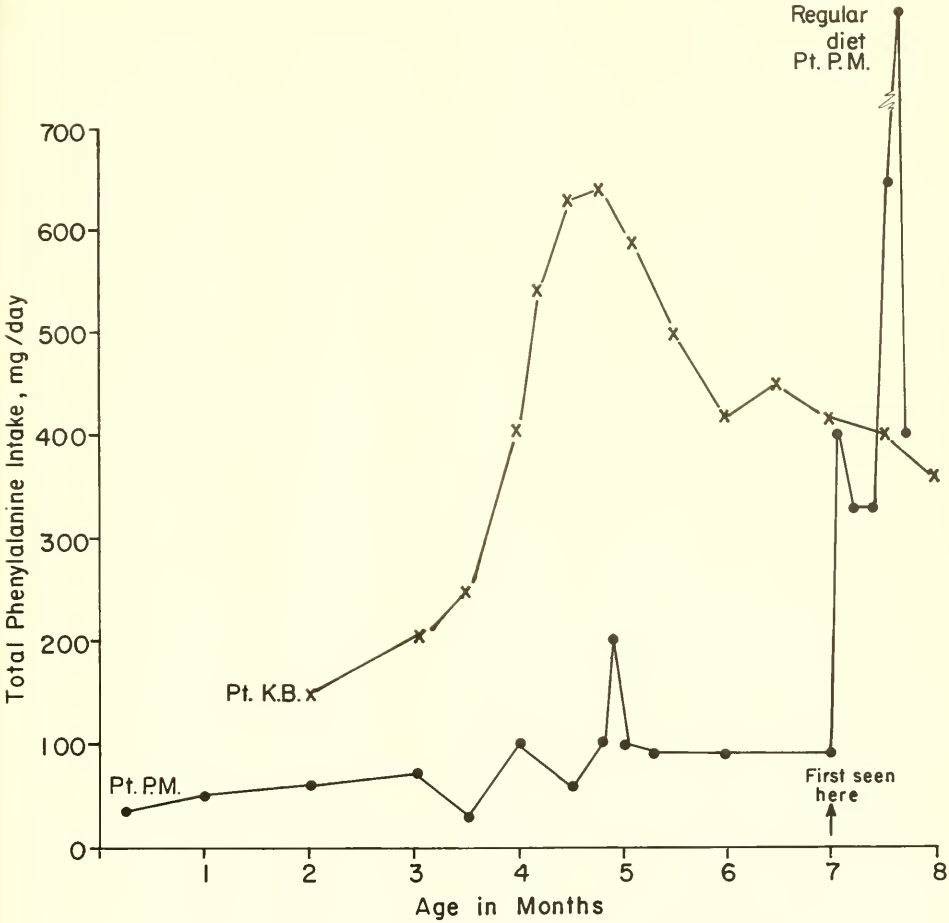
O - chopped fresh fruit, mashed home cooked foods

P - dry cereal, wafers

Before end of first year managed piece of celery, pieces of ripe fresh fruits, raw tomato, etc. and was well on the way to self-feeding in spite of low phenylalanine diet. Appetite appeared to be satisfied, pleased by his own accomplishments. Weight and height followed approximately the 75 percentile curve throughout.

Note: It must be pointed out that the increments of natural foods appear large on this graph. Actually they amount to very small protein increases. Diet contained 3-4 grams protein in the early stages, 4-6 g after 3 months, 8-10 g at 4-5 months of age. Latter half of first year, approximately 4.5 g.


Pt. P.M. Correction Period
500-1200mg
Regular diet
Phenylalanine Intake, mg/day
300
200
100
Lofenalac only
Serum Phenylalanine mg/100cc
8
7
6
5
4
3
2
1
0
Preferred Range
First seen here
Dec. 19
23
26
29
Jan 3
8
10


Regular
diet
Pt. P.M.
700
600
500
400
300
200
100
0
Total Phenylalanine Intake, mg/day
Pt. K.B.
Pt. P.M.
First seen
here
1
2
3
4
5
6
7
8
Age in Months

11. Febrile Illness

Give approximately 1 1/2 times average daily intake of phenylalanine

Lofenalac formula ad lib

Water ad lib

Divide phenylalanine allotment into 4-5 small feedings/ day

Ex.: 175 mg. incr. to 265 mg.

(Young infants)	amt.	mg.
Lofenalac formula (1 T/3 oz. water)	6 oz.	15
Weak tea	8 oz.	
Skim milk	5 oz.	250
Cola, water, etc.	4-5 oz.	
		265

(Young Infants)		
Lofenalac formula (1 T/3 oz. water)	6 oz.	15
Jello water	5 oz.	50
Skim milk	4 oz.	200
Additional free fluids		
		265

200 incr. to 300

Lofenalac formula N.D.	15 oz.	57
Orange juice	4 oz.	40
Saltines	2	40
Tea with evaporated milk	3 T	165
		302

Lofenalac formula N.D.	16 oz.	60
Beef Bouillon,	1 cube	25
Oyster crackers	10	50
Jello, 4 T., whipped with evap. milk, 2 T		110
Gingerale, cola, etc.		
Orange juice, 1 1/2 oz.		15
		300

225 incr. to 337

Lofenalac formula N.D.	9 oz.	34.2
Beaten egg, vanilla	1 oz.	305
Gingerale, cola, etc.		
		339

Lofenalac formula N.D.	20 oz.	75
Beef Noodle Soup	3 oz.	165
Toast 1/2 slice		50
Orange juice	5 oz.	50
		340

275 incr. to 412

Lofenalac formula N.D.	30 oz.	112
Tomato juice, 1/2 cup	4 oz.	50
Potato soup, Mash. potato & milk - Pot.	4 T.	
Milk	4 oz.	200
Other free fluids		
		412

12. Functions, Services and Contributions of the Nutritionist in M.R. Clinic Programs

by

Barbara Umbarger

I. Patient Interviews

A. Possible methods of selection

1. Interview or home visit based on physician's referral because of complaints or recognized difficulties in the area of nutrition or eating habits; or

2. Survey of each child's past and present feeding history as a regular feature of the diagnostic work-up--(comprehensive questionnaire); or

3. Routine interview for each child entering clinic under 4 years of age, consultation with physician regarding children with special problems.

B. Objectives

1. Evaluation of nutritive content of present food intake and report of relative adequacy thereof.

2. Evaluation of child's mechanical abilities in the area of eating

3. Investigation of specific inabilities by first-hand observation of child in an actual eating situation. Feeding demonstration.

4. Evaluation and investigation of the aptness of parental planning, attitudes, practices and expectations in the area of child's eating.

5. Supportive counseling of parents in their role as it pertains to meeting the child's feeding and food needs.

6. Reliable references and printed materials for home use.

7. Practical information on food preparation and economics where needed.

II. Management of Prescribed Therapeutic Regimes

A. Galactosemia

B. Obesity

C. Undernutrition

D. Phenylketonuria

E. Other inborn errors of metalbolism where specified

F. Epilepsy

G. Allergies

H. Constipation

III. Interaction with Staff Members

A. Securing pertinent supplemental information regarding an individual child and his family

B. Contribution to other clinic disciplines of general or specific observations made during nutrition interview.

C. Assistance in instrumenting nutritionist's recommendations and as an avenue of communication or follow-up.

D. Combined-purpose home visits, accompanied by nurse, social worker, etc.

E. Combined-purpose consultation and planning with outside agencies dealing with M.R. clinic patients.

F. Mutual educational exchange, current developments in allied fields.

G. Project planning, cooperative research.

H. Attendance and participation in patient conferences.

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Table II

Typical Uses of Lactose

Simulated mother's milk--infant food Formulas

Health foods--geriatric foods

Diabetic and dietetic preparations

Reducing excessive sweetness in icings, candies, preserves and fruit pie fillings.

Pie crusts and pie fillings

Cakes and sweet rolls

Cookies and cookie sandwich fillings

Sweetened condensed milk

Caramels, fudge and tableted candies

French fries and corn curls

Canned and frozen vegetables

Instant potatoes

Canned and frozen fruits

Instant Coffee

Powdered coffee cream

Pharmaceutical bulking agent, filler and excipient

Tinctures

Hypodermics

Tablets--pharmaceutical and food

Vitamin and mineral mixtures

Easter egg dyes and dye carrier

Meat products

Spice blends

Buttermilk

Modified skim milks

Cottage cheese and cottage cheese dressings

Starter cultures

Cheese foods and spreads

Sour cream

Party dips

Salad dressings

Sherbets, frozen desserts, and ices

High solids ice cream

Dried soups

Monosodium glutamate extender

Penicillin and other antibiotics

Powdered soft drinks

Puddings

Cordials and liquors

Vitamin C and citric acid mixtures

Table III

Foods Which May be Included and Excluded in a Galactose "Free" Diet

TYPE OF FOOD	FOOD INCLUDED	FOOD EXCLUDED
Milk and Milk Products	None, Nutramigen* and soya bean milks used in place of milk.	All milk of any species and all products containing milk as skim, dried, evaporated, condensed yogurt, cheeses, ice creams, sherbets, malted milk.
Legumes	All may be included if facilities are available for monitoring erythrocyte galactose-1-phosphate.	
Meat, Fish, Fowl	Plain beef, chicken, fish, turkey, lamb, veal, port, ham.	Creamed or breaded meat, fish, or fowl; sausage products such as wieners, liver sausage; cold cuts which contain milk; organ meats as liver, pancreas, brain.
Eggs	All	None
Vegetables	Artichokes, asparagus, green beans, beets, broccoli, cabbage, carrots, cauliflower, celery, chard, corn, cucumber, eggplant, kale, lettuce, mustard, okra, onions, parsley, parsnips, pumpkin, rutabagas, spinach, squash, tomatoes.	Sugar beets, peas, lima beans; creamed, breaded, or buttered vegetables; canned or frozen vegetables or corn curls if lactose added during processing.
Potatoes and Substitutes	Irish potatoes, sweet potatoes, yams, macaroni, noodles, spaghetti, rice	Any creamed, breaded, or buttered; French fried potatoes and instant potatoes if lactose added during processing.
Breads and Cereals	Any that do not contain milk or milk products.**	Prepared mixes as muffins, biscuits, waffles, pancakes; some dry cereals, instant cream of wheat.*** Read labels carefully. Dry cereals with added skim milk powder.

*Manufactured by Mead Johnson and Company, Evansville, Indiana.
**In each area, bakeries should be contacted and a list of acceptable products made available.
***Instant cream of wheat contains less than one-tenth of 1 per cent lactose.

TABLE III--Continued

TYPE OF FOOD	FOOD INCLUDED	FOOD EXCLUDED
Fats	Margarines*** which do not contain milk or milk products, oils, shortenings. Dressings which do not contain milk or milk products, bacon.	Margarines and dressings containing milk or milk products; butter, cream cheese.
Soups	Clear soups, vegetable soups which do not contain peas or lima beans, consommes.	Cream soups, chowders, commercially prepared soups which contain lactose.
Desserts	Water and fruit ices; jello; angel food cake; homemade cakes, pies, cookies from acceptable ingredients.	Commercial cakes and cookies and mixes; custard, puddings, ice cream made with milk; any containing chocolate.
Fruits	All fresh, canned, or frozen that are not processed with lactose.	Any canned or frozen that are processed with lactose.
Miscellaneous	Nuts and nut butter, unbuttered popcorn, olives, pure sugar candy, jelly or marmalade, sugar, karo, carob powder, chewing gum.	Gravy, white sauce, chocolate, cocoa, toffee, peppermints, butterscotch, caramels, molasses candies. Instant coffee, powdered soft drinks, monosodium glutamate, some spice blends.

***Mother's, Hollywood margarines in Los Angeles area.

Note: In all instances labels should be carefully read and any product which contains milk, lactose, casein, whey, dry milk solids or curds should be omitted.

Lactate, lactic acid, lactalbumin and calcium compounds do not contain lactose.

FILMS ON MENTAL RETARDATION SHOWN

1. Beyond the Shadows

   26 minutes, color, 1959

   Western Cine Productions

   114 East Eighth Street

   Denver 2, Colorado

2. PKU--Preventable Mental Retardation

   15 minutes, color, 1961

   International Film Bureau

   332 South Michigan Avenue

   Chicago 4, Illinois

3. The Public Health Nurse and the Mentally Retarded Child

   24 minutes, color, 1954

   International Film Bureau

   332 South Michigan Avenue

   Chicago 4, Illinois

PROGRAM OF THE MENTAL RETARDATION INSTITUTE

Wednesday, March 20, 1963

Netherland Hilton Hotel

Morning Session

10:00 A. M. to 12:00 Noon — Chairman: Miss Barbara Umbarger
Children's Hospital Research Foundation, Cincinnati

Welcome and Plans for the Conference

Greetings: Effie O. Ellis M.D., Acting Chief, Division Maternal and Child Health, Ohio Department of Health

J. Wylie McGough. M.D., Assistant Commissioner of Mental Hygiene, Ohio Department of Mental Hygiene and Correction

An Overview of Public Health Programs and Services to the Mentally Retarded

Rudolf P. Hormuth, Specialist in Services for Mentally Retarded Children, Children's Bureau, Department of Health, Education and Welfare, Washington, D.C.

An Overview of Mental Retardation from the Viewpoint of Parents' Needs

Gunnar Dybwad, J.D., Executive Director National Association for Retarded Children, Inc., New York, N.Y.

Development of Feeding Patterns in Children

Effie O. Ellis, M.D., Acting Chief, Division Maternal and Child Health, Ohio Department of Health

Afternoon Session

Chairman: Miss Mary Reeves, Nutrition Consultant, Children's Bureau, Chicago

1:30 P. M. to 5:00 P. M. — The Clinical Team and the Retarded Child

Three Case Presentations:

Jack H. Rubinstein, M.D., Director Hamilton County Diagnostic Clinic and Staff

Miss Shirley Fischer	Public Health Nurse
Miss Jeannette Allen	Social Worker
Mr. Charles Keohan	Social Worker
Lusia Hornstein, M.D.	Pediatrician
Jane Perrin, M.D.	Pediatrician
Dorothy Sievers, Ph.D.	Psychologist
Miss Frances Gunter	Psychologist
Miss Barbara Umbarger	Nutritionist

Group Discussion

Group I
- Leader: Miss Frances Shoun, Assistant Chief of Nutrition Section, Children's Bureau Washington, D.C.
- Recorder: Miss Virginia Jones, Nutrition Consultant Ohio Department of Health

Group II
- Leader: Mrs. Helen Hille, Institution Nutrition Consultant, Children's Bureau, Washington, D.C.
- Recorder: Mrs. Ethel Patterson, Nutrition Consultant, Ohio Department of Health Cuyahoga Falls

Group III
- Leader: Miss Margaret Dunham, Chief, Nutrition Service Unit Ohio Department of Health, Columbus
- Recorder: Mrs. Mary Irene Confer, Nutrition Consultant Dayton Division of Health, Dayton, Ohio

Evening Session

Continental Room

6:00 P. M. Social Hour and Dinner

Presiding: Jack H. Rubinstein, M.D.

Endemic Cretinism - A Travelogue

Josef Warkany, M.D., Professor of Research Pediatrics, College of Medicine, Children's Hospital Research Foundation, Cincinnati

Thursday, March 31

Auditorium - The Children's Hospital Research Foundation Building, Elland Avenue

Morning Session

Chairman: Effie O. Ellis, M.D.

Greetings: A. Ashley Weech, M.D., Director, Children's Hospital Research Foundation

9:15 A. M. to 11:00 A. M. Panel Presentation: Feeding the Mentally Retarded Child with Multiple Handicaps

Ernest Johnson, M.D., Director of Physical Medicine, Ohio State University, Columbus
Mrs. Barbara Ostermeier, Physical Therapist, Clinton County Department of Health, Wilmington, Ohio
Miss Ruth Hadra, Occupational Therapist, United Cerebral Palsy of Cincinnati

Bernard Schlanger, Ph.D., Professor of Speech and Hearing, Ohio State University, Columbus
Miss Doris Lauber, Nutritionist, Maricopa County Health Department, Phoenix, Arizona
Robert Holle, D.D.S., Director, Dental Clinic, Children's Hospital, Cincinnati; Instructor, Dentistry, University of Cincinnati, College of Medicine; Executive Director, Children's Dental Care Foundation, Cincinnati
Discussion Leaders: Mrs. Laura Dittmann, Specialist in Growth and Development of Handicapped Children, Children's Bureau, Department of Health, Education and Welfare, Washington, D.D.

11:15 A. M. Visit to Hamilton County Diagnostic Clinic and Children's Hospital Research Foundation; Children's Hospital

Afternoon Session

Chairman: Jack H. Rubinstein, M.D.

2:15 P. M. to 5:00 P. M. Inborn Errors of Metabolism

Stanley Wrights, M.D., Associate Professor of Pediatrics, University of California Medical Center, Los Angeles

Application of the Principles of Dietary Treatment

1. Galactosemia - Mrs. Phyllis Acosta, Nutrition Consultant, Child Development Clinic, Children's Hospital, Los Angeles, California
2. Ketogenic Diet - A Case Report: Michael De Lorenzo, M.D., Resident, Children's Hospital, Cincinnati
   Mrs. William Timmer - mother
3. Phenylketonuria - Metabolic Research Team of Children's Hospital, Cincinnati: Research Associates Children's Hospital Research Foundation:
   Betty Sutherland, M.D., Pediatrician
   Mrs. Helen Berry, Biochemist
   Miss Barbara Umbarger, Nutritionist

Evening Session

7:30 P. M. to 9:00 P. M. Film Review - Netherland-Hilton Hotel

P. K. U. - Preventable Mental Retardation

The Public Health Nurse and the Retarded Child

Beyond the Shadow

Friday, March 22

Netherland-Hilton Hotel

Morning Session

Chairman: Miss Frances Shoun, Children's Bureau, Washington, D. C.

9:00 A. M. to 11:30 A. M. How Nutritionists are Working in Mental Retardation Programs

In Clinics: Mrs. Patricia Ernest, Pediatric Dietitian, University of Kansas Medical Center, Kansas City
Mrs. Elizabeth Read, Nutritionist, Oklahoma Mental Retardation Center, Tulsa

Follow-up Services in the Home; Mrs. Florence Scott, Nutrition Consultant, Oregon State Board of Health, Portland

In Community Programs: Miss Dorothy Hacker, Nutrition Consultant, New Mexico Department of Public Health, Santa Fe
Mrs. Jeanette Pelcovits, Nutritionist, Prince George's County Health Department, Cheverly, Maryland
Miss Mayton Zicketoose, Nutrition Consultant, Delaware State Board of Health, Dover

In Research and Studies: Mrs. Phyllis Acosta

Afternoon Session

Chairman: Miss Margaret Dunham, Ohio Department of Health, Columbus

1:00 P. M. The Preparation of Nutritionists and Dietitians for Work with Mentally Retarded Children

Pre-service Training
Discussants: Juanita Eagles, Ed.D., Chairman of the Course Directors of Graduate Programs in Public Health Nutrition, School of Public Health, University of Pittsburgh, Pittsburgh, Pa.

Mrs. Patricia Ernest, American Dietetic Association, Internship Director, University of Kansas Medical Center, Kansas City, Kansas.

In-service Training: Mrs. Ansta Barr, Nutrition Consultant, Children's Bureau, Region VII, Dallas, Texas

Summary and a Look to the Future: Miss Mary Egan, Chief, Nutrition Section, Children's Bureau, Washington, D.C.

PROGRAM COMMITTEE

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Miss Barbara Umbarger, Research Foundation, Children's Hospital

Miss Margaret Dunham, Ohio Department of Health
Miss Frances Shoun, Children's Bureau, Washington, D.C.
Miss Mary Reeves, Children's Bureau Regional Office, Chicago

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